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Social Cognition and Behaviour in Dementia of the Alzheimer Type

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Table of Contents

List of Tables

List of Figures

Abstract

Behaviour changes including apathy, disinhibition, irritability or social skills difficulties are commonly reported in individuals following an acquired brain injury (ABI) or presence of a neurodegenerative condition. In addition, there is evidence that these behaviour changes are related to increased caregiver burden and early nursing home and hospital admissions. Yet, very little is known about possible factors relating to behaviour change in ABI or neurodegeneration. Social cognition difficulties have been proposed as possible predictors of behaviour change in ABI or neurodegeneration. However, the evidence for the existence of a link between behaviour and social cognition remains weak. The aims of the current thesis were twofold; firstly, it aimed to systematically examine the current evidence on the link between social cognition and behaviour change in ABI or neurodegeneration. Secondly, the thesis aimed to assess the relationship between social cognition and behaviour change in the context of relationship quality in a sample of 27 individuals with a diagnosis of Dementia of the Alzheimer Type (DAT) or mixed DAT and vascular dementia and their co-residing partners. A review of the current literature showed a discrepancy in the evidence for an association between behaviour change and social cognition between ABI and neurodegenerative participant samples. The link between social cognition and behaviour changes in ABI, although suggested, was not found in the three included studies. However, this was not the case for neurogenerative samples. Although most of the included studies focused on a particular condition, frontotemporal dementia (FTD), evidence for this link was also present in one study focusing on DAT.

Following from this review, the present thesis examined the existence of this association further in individuals with DAT/ mixed dementia. The study used partners' reports on behaviour and relationship quality and examined their associations with individuals with DAT/mixed dementia's performance on a social cognition task. Although the DAT/mixed dementia group showed an impaired performance on a social cognition task compared to their partners, there were no significant relationships between reported behaviour changes, relationship quality and social cognition performance in individuals with DAT/mixed dementia. These findings suggest that despite previous literature indicating a link between behaviour change and social cognition in DAT or mixed dementia, this relationship is yet to be fully established in this population and further research is needed to inform current practice and models of behaviour change in neurodegeneration. The present findings are also discussed with regards to implications for clinical practice and adaptations in psychotherapy for people with DAT or mixed dementia and their partners.

1. Overview

The current thesis consists of two papers. Paper A is a systematic review of the current literature regarding the relationship between social cognition and behaviour in acquired brain injury (ABI) or neurodegenerative conditions. Despite the increasing evidence regarding the existence of a link between behaviour and social cognition in neurodegenerative conditions and ABI, this is the first systematic review to examine the association and make comparisons across studies. Evidence for this association remains weak, particularly in individuals with ABI. None of the studies with individuals with ABIs included in the systematic review found a significant association. Although studies on neurodegenerative conditions appeared more successful at establishing this link, most of these studies focused on one particular population, individuals with a diagnosis of frontotemporal dementia (FTD). Only one study (i.e. Shimokawa et al., 2001) examined this association in Dementia of the Alzheimer's Type (DAT). The present systematic review describes some of the limitations of the studies included and highlights the need for further methodologically sound research in the area of ABI and neurodegeneration.

Paper B attempts to address some of the limitations described in the Systematic Review and examines behaviour change, social cognition and relationship quality in 27 individuals with a diagnosis of DAT or mixed Vascular and DAT and their co-residing partners. The study shows that individuals with DAT/mixed dementia's performance on a social cognition task is significantly impaired in comparison to their partners. Regarding the link between behaviour

change and social cognition, the study does not find significant associations. The paper attempts to describe these results in the context of the current evidence. The quality of the relationship between partners and individuals with DAT/mixed dementia is also examined and some associations found with behaviour change. These results along with implications for clinical practice and current legislation are discussed in detail.

2. Systematic Review:

Are difficulties in social cognition in individuals with brain injury, stroke or neurodegenerative conditions related to subsequent changes in behaviour? A systematic review.

Running head: Social Cognition and Behaviour

Are difficulties in social cognition in individuals with brain injury, stroke or neurodegenerative conditions related to subsequent changes in behaviour? A systematic review.

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This article followed the author's guidelines from the journal 'Neuropsychologia'. Tables have been kept in the corresponding position in text for ease of reading and correcting, but will be formatted according to guidelines before submission.

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Abstract

The present systematic review investigates the relationship between social cognition and behavioural changes in individuals following a traumatic brain injury, stroke or a neurodegenerative condition. Studies that assessed the variables of social cognition and behaviour changes within a single study were identified through a systematic search using electronic search engines, manual journal searches and reference list searches. A total of thirteen studies were selected for this review. However, only eleven of the included studies directly addressed the link between aspects of social cognition and behaviour in acquired brain injury, stroke or neurodegenerative diseases. The remaining two speculated a link. Eight of the studies found a significant association between behaviour change and social cognition. Interestingly, this association was only found in neurodegenerative participants, predominantly in frontotemporal dementia. The present review highlights several methodological issues, which limit the conclusions that could be drawn. The results of these studies are discussed in the context of implications for support and rehabilitation following acquired brain injury or a neurodegenerative disease and recommendations for future studies are offered.

Keywords: Social cognition, emotion recognition, behaviour, acquired brain injury, neurodegenerative conditions, systematic review.

Highlights

- First review on the relationship between social cognition and behaviour change
- Traumatic brain injury, stroke or neurodegenerative condition samples included
- Limited evidence for existence of this link
- Methodological issues of studies included make comparisons across studies difficult
- Further methodologically sound studies needed

2.1. Introduction

Social cognition refers to an individual's ability to understand, process and adaptely respond to social cues present in an individual's social environment. It encompasses a wide range of functions, including and individual's capacity to appreciate emotion, both in self and others, understand people's desires and intentions (Theory of Mind), regulate their behaviour and be flexible in social interactions (Kipps, Mioshi & Hodges, 2009a). Research into the neuroanatomical correlates of social cognition, has revealed a predominance within the prefrontal cortex of the brain, in particular the orbitofrontal cortex as well as subcortical brain regions, such as the amygdala (Shany-Ur et al., 2013). Interestingly, the prefrontal cortex appears to also be related to behaviour changes, including different forms of aggression, among others (Blair, 2004). Some authors have hypothesised a link between social cognition and behaviour changes, on the grounds that individuals who struggle to process social situations may behave in ways that are deemed socially inappropriate (Jackson and Moffat, 1987), and at times challenging for professionals or families around them. Such changes in behaviour are relatively common following damage to the frontal lobes; as in the case of head trauma, ischaemia, haemorrhage or a neurodegenerative disease, among others. The present review aims to systematically evaluate the current evidence for the existence of a link between behaviour change and social cognition in individuals following an acquired brain injury (ABI) or onset of a neurodegenerative condition.

2.1.1 Behaviour Change following Acquired Brain Injury

Significant changes in emotional and social behaviour can occur after an

acquired brain injury (ABI), including traumatic brain injury (TBI) or stroke among others (Fellows, 2007; Hutter, 2000). These changes can comprise impaired social judgement, difficulty recognising and understanding other people's feelings, impulsivity, emotional lability, communication problems and apathy (Kendall & Terry, 1996; Kneebone & Lincoln, 2012; Levin, 1995; Morton & Wehman, 1995). They can have severe psychosocial consequences including a negative impact on rehabilitation goals (Bond & Brooks, 1976; Tate & Broe, 1999; Tate et al., 1989; Weddell, Oddy, & Jenkins, 1980), ability to return to or maintain work and preservation of meaningful significant social relationships with others (Ownsworth & McKenna, 2004). Behavioural changes are associated with family and caregiving burden; more so than any physical and cognitive changes that individuals with TBI may experience (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Kinsella, Packer, & Olver, 1991). In a study looking at cognitive and behaviour changes following stroke, caregivers rated behaviours such as uncooperativeness, sadness or depression and anger as the most difficult to manage (Clark & King, 2003).

There is evidence that frontal lobe damage is related to behaviour change (Beer, John, Scabini & Knight, 2006). However, there appear to be differences in the behaviour displayed by individuals depending on the area of the prefrontal cortex that has been primarily affected. Damage to the lateral prefrontal cortex appears to be linked with impaired cognitive control, difficulties with attention, working memory, response monitoring and planning (Beer, Knight, Shimamura, 2004; D'Eposito, Postle & Rypma, 2000; Wagner, Burge & Badre, 2004); generally referred to as dysexecutive syndrome (Wilson, Alderman, Burgess, Emslie, & Evans, 1996). In

contrast, damage to the orbitofrontal regions appears to be responsible for poor social judgement, impulsiveness and lack of consideration or empathy for others (Miller & Cummings, 2007). Other frequently reported behaviour changes following damage to this area include apathy, restlessness, indifference, euphoria, diminished attention, planning difficulties and impairments of emotional control (Sarazin et al., 1998). Case studies report that orbitofrontal cortex damage has resulted in impaired ability to prioritise solutions to interpersonal problems (Saver & Damasio, 1991), disinhibited behaviour (Rolls, Hornak, Wade & McGrath, 1994) or disruptive behaviour in hospital settings (Beer et al., 2006; Blair & Cipolotti, 2000).

Several theories have been developed in an attempt to explain the link between the orbitofrontal cortex and interpersonal behaviour (e.g., Bechara, Damasio, & Damasio, 2000; Elliott, Dolan, & Frith, 2000; Kringelbach & Rolls, 2004). These theories suggest that two main types of variables can account for the social and behavioural changes commonly associated following orbitofrontal damage: impaired emotional systems, and difficulties with behavioural monitoring (Beer et al., 2006). The somatic marker hypothesis (Damasio, 1996; Bechara et al., 2000) suggests that body biasing signals, or emotions in the current framework, are represented and regulated in an emotion circuitry area of the brain, i.e. the orbitofrontal cortex, in order to help with decision-making processes in complex and uncertain situations. Support for this theory is largely based on an experimental paradigm assessing decision-making abilities, namely the Iowa Gambling Task (IGT, Bechara et al., 1994, 1996). Bechara and colleagues (1994, 1996) reported that, in comparison to healthy controls, individuals with ventromedial prefrontal cortex

damage showed no '*somatic responses'* (i.e. emotion and bodily signlas, measured by skin conductance) or impaired decision-making abilities, suggestive of a possible link between this particular area of the brain and emotion-related decisions.

Other hypotheses have highlighted the role of the orbitofrontal cortex in self-monitoring (Prigatano, 1991; Stuss, 1991), proposing that people make social mistakes due to a lack of insight into the appropriateness of their behaviour. Beer et al. (2006) attempted to integrate these two theories and found support for the hypothesis that damage to the orbitofrontal cortex impairs self-monitoring and thus prevents the generation of emotions needed for successful social interaction; however this finding should be interpreted with care as the total sample included only eight patients and eight controls with various brain damage aetiologies, ranging from TBI to stroke. This is particularly pertinent, considering that in studies including stroke or TBI samples, individuals may not present with discreet damage to one particular area, making comparisons between individuals difficult.

2.1.2 Behaviour Change following Onset of a Neurodegenerative Condition

Although described at different stages of disease progression, changes in social and emotional behaviour are commonly reported in neurodegenerative conditions (Chow et al., 2009; Seeley et al., 2007). Behaviour changes in neurodegenerative conditions are usually associated with the right hemisphere (Palmieri et al., 2010; Rankin et al., 2009; Rosen et al., 2005), These behaviour changes are often similar to those observed in patients with known social cognitive deficits (Stone et al., 1998), and can include apathy, reduced empathy and disregard

for social norms (Fernandez-Duque et al., 2010; Girardi, Macpherson & Abrahams, 2011; Henry et al., 2009; Strong et al., 2009).

Amongst neurodegenerative conditions, the most severe changes in behaviour are usually seen in individuals with frontotemporal dementia (FTD) (Gregory et al., 2002), particularly in individuals with predominant frontal lobe involvement, also known as fronto-variant FTD (bvFTD) (Gregory et al., 1999; Hodges et al., 1999; Hodges & Miller, 2001a, b). There is a general consensus that FTD presents on a continuum, ranging from temporal presentation, as in semantic dementia, to a frontal form, as in bvFTD (Hodges et al., 1992). Whilst the temporal form consists primarily of language and memory difficulties, the frontal form is characterised by a dysexecutive syndrome and changes in personality and behaviour (Cummins & Benson, 1992).

Behaviour changes in FTD include a lack of empathy or concern for others, apathy, disinhibition, socially inappropriate behaviour and loss of insight (Lund and Manchester Groups, 1994; Gregory & Hodges, 1996). Frontotemporal dementia shares many clinical, radiological and pathological features with the atypical parkinsonian movement disorders such as Corticobasal Degeneration (CBD) or Progressive Supranuclear Palsy (PSP) (Cordato et al., 2005). Progressive atrophy to frontal-subcortical regions in these conditions may explain some of the socio-emotional changes reported (Litvan, Cummings & Mega, 1998). Individuals with a diagnosis of Dementia of the Alzheimer's type (DAT, DSM-V, 2013), who may also show extensive damage to the ventromedial and prefrontal cortex (Van Hoesen, Parvizi & Chu, 2000), have also been found to show non-memory related behaviour

changes such as agitation, apathy, mood changes, hallucinations or delusions (Jalbert, Daiello & Lapane, 2008). This collection of changes in behaviour and personality following the onset of dementia has received the name of Behavioural and Psychological Symptoms of Dementia (BPSD; Finkel, Costa e Silva, Cohen, Miller & Sartorius, 1997). Several studies have suggested a link between those changes and the widespread disruption of cortical and subcortical neural systems involving the orbitofrontal cortex (Van Hoesen, Parvizi & Chu, 2000).

2.1.3 Relationship between Behaviour Change and Social Cognition

Despite the increasing amount of literature available on the impact of behavioural, emotional and social changes following ABI, or neurodegenerative conditions, very few studies have investigated possible predictors underlying such changes (Kipps, Mioshi & Hodges, 2009a; Milders, Fuchs & Crawford, 2003). An understanding of possible predictors and related variables is essential in improving support provision and management of these behaviour changes.

Poor social cognition skills, including emotion identification abilities, have been proposed as possible predictors of behaviour change. From an evidence-based psychotherapeutic perspective, the links between behaviour and emotion have been of central importance in understanding and promoting various types of therapeutic change (Greenberg & Saffran, 1989). For instance, behavioural activation, which relies on scheduling pleasant activities to improve mood (Veale, 2008), clearly links an individual's emotional state with their behaviour. The evidence base for this type of therapy, particularly for depression, is robust and has led to the development of

several other types of psychotherapies for a wide range of psychiatric disorders (National Institute for Clinical Excellence, NICE, 2009). Therefore it seems plausible that individuals who struggle to identify their own or others' emotions may also show changes to their behaviour.

Jackson and Moffat (1987) found that individuals with TBI had difficulties identifying facial emotions and emotional postures, and hypothesised a possible link between recognising emotional expressions and social behaviour following TBI. The relationship however was not explicitly assessed. Cicerone and Tanenbaum (1997) found evidence of difficulty with social cognition in a TBI patient with damage to the left orbitofrontal cortex presenting with emotion and behaviour changes and suggested a link between behaviour and emotion was possible. Furthermore, Blair and Cipolotti (2000) described a patient with orbitofrontal damage and behaviour changes, impaired on facial emotion recognition tests and other social cognition measures, such as identifying socially inappropriate behaviour from stories of social situations. Although these studies suggest a possible link exists between behaviour and emotions, it is difficult to generalise results from a case study alone.

From a social perspective, it makes sense that in order to interact with others, individuals need intact social cognition skills; they need to be able to perceive and process social signals concerning others' emotional states and intentions as well as formulate appropriate responses to these signals (Kipps et al., 2009a). This is the basic idea behind Social Signal Processing (SSP), a new research and technological domain aimed at providing computers with an ability to sense and understand human social signals (Vinciarelli et al., 2008, Vinciarelli, Pantic & Bourlard, 2009).

Essential to SSP, is the phenomenon of Theory of Mind (ToM), which refers to individuals' abilities to make inferences about others' mental states and appears to underlie humans' ability to engage in complex social interactions (Stone, Baron-Cohen & Knight, 1998).

Results from lesion studies have yet to provide conclusive evidence regarding possible neuro-anatomical areas critical for ToM (Stone et al., 1998). There is evidence that individuals with primary orbitofrontal damage can show significant social functioning difficulties, such as those found in individuals with autism (Stone et al., 1998). Based on their results and Baron-Cohen's (1995) definition of ToM as a multicomponent concept, Stone et al. (1998) proposed that ToM was unlikely to be localised in a single area of the brain and suggested a distributed circuit involving regions of the frontal cortex as well as the limbic system.

With the development of imaging techniques, researchers have continually aimed to isolate the neural basis of ToM (Shamay-Tsoory & Aharon-Peretz, 2007). Shamay-Tsoory and Aharon-Peretz (2007) suggested a novel neurobiological model of ToM and distinguished two major anatomical sub-components involved in ToM: the cognitive and the affective mentalising components. These components were described as dissociable yet interacting prefrontal networks, both of which are required for social interaction (Shamay-Tsoory & Aharon-Peretz, 2007).

2.2. Present Review

Until now, no systematic review has explored the relationship between social cognition and behavioural changes following ABI or a neurodegenerative condition.

The aim of the present review was to systematically evaluate studies investigating or measuring aspects of social cognition and behaviour change within a single study, in individuals with ABI or neurodegenerative condition, and determine whether methodological differences may have contributed to the mixed findings in relation to the variables. Due to the scarcity of studies investigating behaviour and social cognition in ABI or neurodegenerative conditions alone, the present review included studies recruiting participants with either or all of those aetiologies.

2.3. Methodology

The present systematic review followed the guidelines proposed by the Centre for Reviews and Dissemination (CRD, 2009). Due to the nature of the studies included in this review being mainly observational, the present systematic review was based on the reporting checklist of Meta-analyses of Observational Studies in Epidemiology (MOOSE, Stroup et al., 2000), subject to relevant study specific modifications.

2.3.1 Inclusion and Exclusion Criteria

The inclusion criteria were: a) studies published in English, b) studies are original publications, c) descriptive, quantitative, observational studies (e.g. cross-sectional or case-control studies), d) studies suggest a relationship between changes in social cognition abilities and behavioural changes (as described in the behavioural component of BPSD in dementia populations), e) participants' behaviour is measured by a partner, carer or clinician using a standardised measure; such as the Neuropsychiatric Inventory (NPI, Cummings, 1997), f) Studies may assess one or all

aspects of social cognition, including ToM, and its relationship to behaviour in a neurodegenerative condition, brain injury or stroke.

The exclusion criteria were: a) Reviews and treatment studies, b) Studies which do not assess social cognition or behaviour, c) Participants' other than those with a diagnosis of a progressive neurodegenerative condition, brain injury or stroke, d) Studies including participants with co-morbid presentations such as Autism/ Asperger's, Personality Disorder or diagnosis of learning disability.

2.3.2 Search Strategy

The primary author of this review (BP) conducted an initial literature search in September 2012 using the Database of Abstracts and Reviews of Effects (DARE) and the Cochrane Database of Systematic Reviews (CDSR). The search string used included variations of the three main terms: '*social cognition*' AND '*behavioural problems*' AND '*brain disorder'* (Table 2.1). The search did not reveal any reviews similar in nature; therefore, further searches in other sites such as the National Insitute for Clinical Excellence (NICE) or the Scottish Intercollegiate Guidelines Network (SIGN) were also conducted. Again, no systematic review looking at the links between the proposed terms was produced, which highlights the existing gap in the literature.

Searches were initially limited to studies published in peer-reviewed journals in the English language. Searches included both American and British spellings. An initial search of the literature in September 2012 showed very few studies looking at

social cognition, behaviour and neurodegenerative conditions alone (EMBASE, n=32, PsycINFO, n= 322 and Medline, n= 69). Therefore, the term '*social cognition*' was expanded to include other possible variations of this term used in similar studies. Key words from other studies were also searched and '*emotion recognition*' included. Additionally, it was decided to expand the participant population criteria to include other brain-related conditions such as brain injury or stroke in addition to neurodegenerative conditions. With regard to behaviour-related search terms, an additional term was included '*behavioural and psychological symptoms of dementia*' (BPSD) as well as '*social skills*' and possible variations of this term (Table 2.1).

Table 2.1. *Search String Used for Each Term in the Systematic Search.*

Term 1		**Term 2**		**Term 3**
'Social cognition' OR 'Emotion$ ADJ3 recognition' OR 'Emotion ADJ3 identification' OR 'Affect$' OR 'Emotion$'	**AND**	'Social behavio?r' OR 'Challenging ADJ3 behavio?r' OR 'Stress$' OR 'Social skills' OR 'Behavio?r$ changes/ problems/ difficulties' OR 'Behavio?r$ and psycholog$ symptoms of dementia' OR 'Agitation'	**AND**	'Neurodegenerative' OR 'Dementia' OR 'Stroke' OR 'Brain ADJ3 ischemi$' OR 'Brain injury' OR 'Head Injury'

Note. $: Truncation symbol,?: American/ British Spelling, ADJ3: terms appearing within three words of each other.

In June 2013, using the search strings in Table 2.1, the following commonly used databases were systematically searched to identify possible studies: EMBASE (1980-2013), PsycINFO (1987-2013) and Medline (1946-2013). The search strings

produced a total of 1746 articles; 1039 articles by PsycINFO, 418 by Medline and 289 by EMBASE. Initially the titles and then the abstracts of the returned articles were screened using the inclusion and exclusion criteria. Twenty-seven articles were provisionally selected. In addition, relevant journal searches between the years of 2000 and 2013 were also carried out. The following journals were selected: Brain, Neuropsychologia and the Journal of Clinical and Experimental Neuropsychology (JCEN). The decision to search these journals was based on the large number of provisional articles that appeared in these journals (four provisional articles appeared in Brain, five in JCEN and six in Neuropsychologia). Journal searches resulted in three additional articles provisionally included.

Finally, the reference section of the provisional articles was also searched, resulting in the inclusion of one additional article. The total number of articles provisionally included in the present review was 31. These 31 articles were fully read and examined, resulting in 19 articles being excluded (see Figure 2.1). A total of 12 articles, i.e. thirteen studies, [an article by Girardi et al. (2011) included two studies and these were treated as two separate studies] were included in the present systematic review. Figure 2.1 shows a flowchart diagram of the literature search.

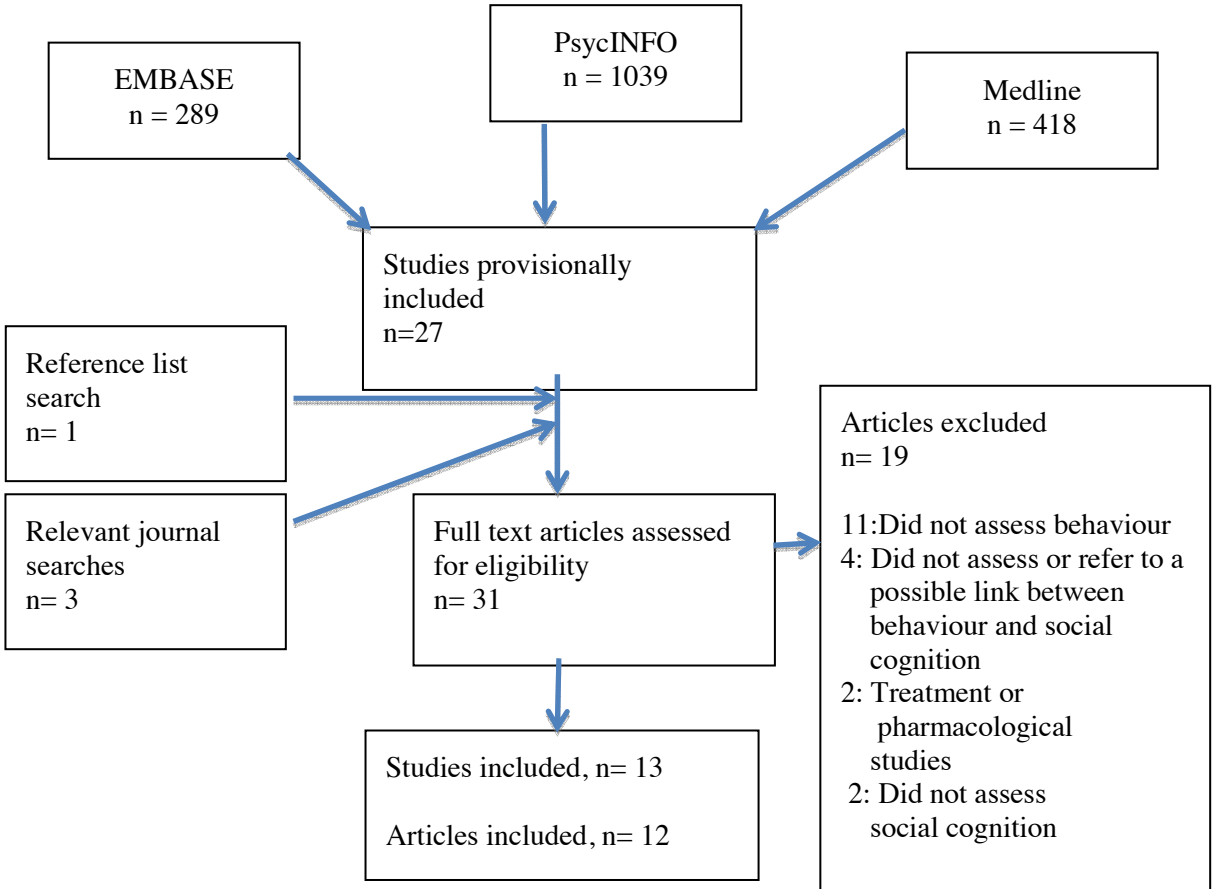

Figure 2.1. *Flowchart of the Study Selection Process*

2.3.3 Quality Assessment

Study quality criteria guidelines such as those proposed by SIGN (2011) or the Consolidated Standards of Reporting Trials (CONSORT), have been primarily developed for studies using a Randomised Controlled Trial (RCT) methodology.

Application of these guidelines was therefore not considered suitable for the present systematic review. Thus, a composite measure intended to assess the quality of the articles in this review was developed and adapted from several guidelines (see Appendix A for a copy of the quality criteria assessment used for this review). The quality criteria for this review incorporated principles from the Clinical Research

Evaluation Tool (CREST, Peck et al., 2006), the Scottish Intercollegiate Guidelines Network (SIGN, Guideline 50) and followed the recommendations proposed by MOOSE (Stroup et al., 2000). The following criteria were selected as relevant to the present review: i) The rationale for investigating emotion identification and behavioural difficulties in stroke, brain injury or neurodegenerative conditions is clearly discussed; ii) The sample is well described and frequencies reported for clinical and demographic characteristics such as age, gender or time since diagnosis. The frequency distribution, central tendency (means, medians, modes and standard deviations) and dispersion (range) of the sample are reported; iii) Caution has been taken to make sure that the number of participants approached, the number of individuals who participated and how the sample was selected is reported and inclusion and exclusion criteria should also be clearly described, iv) When a comparison group is used, an attempt should be made for participants to be matched in relevant aspects other than the factors under investigation, for example age, education or premorbid IQ scores. When groups have not been matched, between group analyses should have been conducted to identify significant differences in demographic characteristics between groups, v) An internationally recognised classification system should be used for individuals included in the research who are identified as having a stroke, a brain injury or a neurodegenerative condition, vi) The study gives an indication of missing data; it indicates how many of the participants in each group who were asked to take part in the study actually managed to complete each or all measures; vii) The study gives a rationale for the choice of tests employed; viii) Attrition rates are reported for each of the groups studied, ix) Reliability and validity are reported for the emotion identification measure; x)

Reliability and validity are reported for assessments looking at an individual's behaviour; xi) Statistical power of the study is addressed; xii) Generalisability of the findings is discussed, as well as implications and limitations of the study.

The twelve quality criteria selected aimed to aid assessment of risk of bias as a result of methodological issues including sampling, power and generalisability. Quality coding was carried out by the first and second authors (BP and FM). Each reviewer assessed the thirteen selected articles to ensure adherence to the coding criteria. Each criterion was assessed using the SIGN 50 (2011) methodology guidelines with following outcome ratings: well covered (3 points), adequately addressed (2 points), poorly addressed (1 point) and not addressed (0 points). The initial agreement between both raters was 90.1 per cent. The main differences lay in criteria 1 and 12, both of which are considered more subjective criteria. Emerging discrepancies were resolved in discussions.

2.4. Results

Data from each of the 13 studies selected were extracted by the first author (BP) in September 2013. A data extraction form obtained the following information for each study: author, date, country, participant characteristics and numbers, aims of the study, behavioural, neuropsychological, mood and emotion recognition measures used and main findings. This form was checked by collaborators (KL, FM & KP) for accuracy before synthesis began.

2.4.1 Data Synthesis

Due to the variability in the methodology employed, sample variety and sample sizes used in the thirteen included studies, quantitative data synthesis, i.e. meta-analysis, was not deemed appropriate. A primarily narrative approach, i.e. a textual approach to the process of synthesis, was taken. To aid the process of description and analysis, as well as to explore possible patterns among studies, the thirteen included studies were disaggregated into two groups: three studies assessing individuals with a TBI or stroke and ten studies assessing individuals with neurodegenerative conditions (Table 2.2).

2.4.2 Quality of the Included Studies

Quality assessment ratings for the thirteen included studies are shown in Table 2.3. Exact comparisons between the studies based on the overall study score used are not advisable due to methodological differences between studies (e.g. use of control sample, different aetiologies, etc.), however the quality assessment criteria provides a useful tool to assess the included studies' methodological strengths and weaknesses in more detail.

Based upon the quality assessment, Hornak et al. (1996) was the least methodologically sound study, scoring 8/36; whilst Milders et al. (2008) was the strongest study methodologically, scoring 18/36. Both these studies included ABI clinical populations. With regards to neurodegenerative sample studies, a study by Gregory et al. (2002), Rankin et al. (2009) and Shimokawa et al. (2001) were rated strongest, all three rated 17/36. Interestingly, there were several criteria that almost all studies failed to address; none of the studies addressed quality criteria #6 'missing data' and #8 'attrition'. In addition, only Shimokawa et al. (2001) comprehensively

covered the psychometric properities of their social cognition measure used, and Gregory et al. (2002) were deemed to 'partially address' this criteria. The remaining eleven studies, did not attempt to provide psychometric properties for the measures utilised. Similarly, only Gregory et al. (2002) and Shimokawa et al. (2001) 'partially address' the psychometric properties of the behaviour measure included. All quality criteria included were considered applicable to the thirteen studies included. However, the rating 'Not applicable' was included in our quality assessment following SIGN 50 methodology. Of the 13 studies included, none of the criteria were considered ´not applicable'.

Only six studies in the present review were found to have quality ratings above 16/36, indicating the poor quality of the studies assessing this relationship.

Quality assessment item 3 encompasses several issues regarding representativeness of the sample selected, presence of inclusion and exclusion criteria and exploration of differences between demographic variables. In addition, item 4 addresses issues of frequency descriptors and matching of samples and item12 includes issues regarding generalisability as well as implications and limitations of the study. As such, it was deemed appropriate to adopt a pro-rated system in the scoring of criteria 3, 4 and 12. A detailed assessment of these three quality criteria revealed only Rankin et al (2009) and Shimokawa et al (2001) clearly defined inclusion and exclusion criteria. All other studies either 'did not address' or 'poorly addressed' this. With the exception of Shimokawa et al. (2001), all studies explored differences in demographic variables between groups and attempted to match

clinical samples to a comparison group. Finally, regarding generalisability, implications and limitations; there were variations with regard to quality assessment of the three aspects; however, common to all three items in criteria 12, none of the studies was rated as 'well covered' on all three items.

Finally, raters (BM and FM) also noted whether or not ethical approval was granted by a relevant committee. Of the 13 studies selected, only five explicitly reported having gained ethical approval.

Table 2.2. *Summary of Studies' Characteristics and Main Findings. Studies Divided by Type of Sample.*

	Author, Date, Country	Participants	Aims of the Study	Measures	Findings
Participants with ABI					
1	Hornak, et al. (1996) UK	Inpatients and outpatients with TBI or stroke n= 23. Age (M=47.8, SD= 14.3) n=12 had damage to ventral parts of the frontal lobes and n=11 did not have damage to this region. Age (M=41.4, SD= 14.6)	Measure responses to face and voice expression, changes in the experience of emotions following brain damage and alterations in behaviour. Behaviour changes were also analysed in relation to impairments in emotional expression identification and to subjective emotional changes.	**Emotion & Social Cognition Measures:** Ekman Faces (Ekman and Friesen, 1976), Tape of Emotional Sounds with Different Tones of Voice, Voice Discrimination Test, Environmental Sounds Test. **Behaviour Measures**: Subjective Emotional Change Questionnaire, Staff Behaviour Questionnaire.	**Behaviour & Emotion recognition**: A correlation was demonstrated between abnormal behaviour and subjective changes in emotional experience in a group of patients with ventral frontal lobe damage who also suffered from expression identification difficulties. No link with staff behaviour questionnaire and emotion recognition measures reported.
2	Milders, et al. (2003) UK	TBI, n=17. Age (M=30.5, SD= 13.3) Controls, n=17. Age (M=29.1, SD= 12.1)	Identify impairments in expression recognition, understanding of situations and intentions and flexibility in patients with moderate to severe TBI. The second aim was to investigate the relationship between these impairments with ratings concerning the patients' behaviour.	**Emotion & Social Cognition Measures:** Ekman Faces (Ekman and Friesen, 1976), Benton Facial Recognition Test (Benton et al.., 1983), FAB, EEQ, Faux Pas Test (Stone et al, 1998), Reading the Mind in the Eye Test (Baron-Cohen et al., 1997). **Behaviour Measures**: NBAP, SIQ. **Cognition Measures**: RFFT, UFO.	TBI group were impaired at recognising facial and vocal expressions of emotions, detecting faux pas and non-verbal fluency. **Behaviour & Emotion recognition**: Impairments were not significantly associated with the relatives' ratings of behavioural problems following TBI, although correlations with detecting social faux pas were relatively high.

3	Milders, et al. (2008) UK	TBI, n=33. Age (M=37.5, SD=16.1 years) Orthopaedic Controls n=34. Age (M=35.6, SD=13.1 years)	Investigate if deficits in emotion recognition, understanding of intentions (Theory of Mind, ToM), or cognitive flexibility underlying changes in social behaviour after TBI.	**Emotion & Social Cognition Measures:** Ekman Faces (Ekman & Friesen, 1976), FAB, Faux Pas Test (Stone et al., 1998), Cartoon Test (Happé et al., 1999). **Behaviour Measures**: NBAP, KAS-R, DEX. **Mood Measures**: HADS. **Cognition Measures**: BSAT, AFT.	Compared to orthopaedic controls, the TBI group proved impaired on expression recognition, ToM, and cognitive flexibility soon after injury and at one-year follow-up. Proxy ratings of behaviour showed an increase in behavioural problems one-year following TBI. **Behaviour & Emotion recognition**: No correlation between emotion recognition or theory of mind test performance and post-injury behaviour at baseline or follow-up were found.
Participants with neurodegenerative conditions.					
4	Girardi, et al. (2011a) UK	ALS, n=19. Age (M=57.8, SD= 15.64) Control, n=20. Age (M=56.8, SD= 0.3)	Study 1: Investigated if there was evidence of a deficit in non-demented ALS patients on a modified version of the IGT, a test of affective decision-making. The relationship between performance and behaviour change was also investigated.	**Emotion & Social Cognition Measures:** IGT **Behaviour Measures**: FrSBe. **Cognition Measures**: NART, GNT, Writing and Spoken Verbal Fluency Test (Abrahams et al., 2000).	Significant difficulties in IGT noted in patients. ALS patients showed no adjustment during IGT or learning of disadvantageous decks in relation to the negative consequence of losing money. **Behaviour & Emotion recognition**: Patients showed an increase in behavioural dysfunction from premorbid to present, with significantly greater levels of apathy than controls and poor performance on the IGT related to overall level of behaviour dysfunction in daily life.

5	Girardi, et al. (2011b) UK	ALS, n=14. Age (M=57.4, SD= 16.0) Controls, n=20. Age (M=54.8, SD= 11.5)	In depth analysis of social and emotional cognition in ALS, its relation to executive functioning and behaviour	**Emotion & Social Cognition Measures:** Judgment of Preference Task (E-Prime Task, from Baron-Cohen et al. 1995 and Snowden et al., 2003), Reading the mind in the Eyes (Baron-Cohen et al., 2001), FEEST. **Behaviour Measures** MBQ, CBI, FrSBe. **Cognition Measures**: WAIS-III, WMS-III, KOLT, GNT, Hayling and Brixton Tests (Burgess & Shallice, 1997), Written or Spoken Verbal Fluency Test (Abrahams et al., 2000).	**Behaviour & Emotion recognition**: A substantial proportion of patients were impaired at inferring mental state of another as determined by eye gaze, resulting in significant differences between ALS and controls in the ToM task. ALS group showed an increase in behaviour dysfunction on the FrSBE from premorbid levels, although the patients did not rate their level of dysfunction highly compared to controls. Evidence of behaviour change in 10/14 described by carers; and the presence of behaviour change strongly overlapped (36%) with social cognition impairments.
6	Gregory, et al. (2002) UK	bvFTD, n=19. Age (44-67, M=58.6, +/- 6.9 years). DAT, n= 12. Age (52-79, M= 66.5, +/- 5.1 years). Healthy controls n=16. Age (52-76, M= 57.1, +/- 5.1 years)	Assess whether patients with bvFTD show impairments in Theory of Mind (ToM) tests. Establish whether deficits in ToM are specific to bvFTD, or also found in DAT. Also, the study aimed to investigate the relationship between performance in ToM tests and frontal and executive tasks as well as degree of neuropsychiatric and behavioural dysfunction in bvFTD.	**Emotion & Social Cognition Measures:** Reading the Mind in the Eyes Test (Baron-Cohen et al., 1997), First/Second Order False Belief Test (Wimmer, 1985; Baron Cohen, 1989), Faux Pas Test (Stone et al., 1998; Baron-Cohen et al., 1999a). **Behaviour Measures**: NPI. **Cognition Measures**: MMSE, ACE, WMS, Rey Complex Figure (Rey, 1941), VOSP, GNT, Pyramids and Palm Trees Test (Howard and Patterson, 1992), FAS, WCST.	bvFTD had significant deficits on the ToM tests. Most bvFTD patients showed deficits on the faux pas tests and the Reading the Mind Eyes Test. DAT patients showed no deficits on the specific ToM-based components of the tasks. **Behaviour & Emotion recognition**: There was a significant negative correlation between NPI and performance on both the second order false belief and faux pas test, suggesting that the degree of ToM was related to the level of neurobehavioural disturbance in bvFTD.

7	Keane, et al. (2002) UK	bvFTD, n=6. Age (M=58.7, SD= 4.8)	The aim of this study was to replicate finding of impaired facial expression in bvFTD and see if such deficits can be accounted for by (a) a general face processing impairment, or (b) a deficit in recognizing emotional signals, regardless of their modality.	**Emotion & Social Cognition Measures:** Benton Facial Recognition Test (Benton et al., 1983), Gaze Processing Task (Keane et al. 2002), Famous Faces Recognition Test (Keane et al., 2002), Ekman Faces (Ekman and Friesen, 1976), Recognition of Vocal Emotions (Keane et al., 2002). **Behaviour Measures**: NPI. **Cognition Measures**: MMSE, NART-R, WCST, FAS, Pyramid and Palm Tree Test (Howard & Patterson, 1992).	People with bvFTD demonstrate preserved ability to recognize faces as familiar and for most cases in this study, to match unfamiliar faces. Severe impairments were found in the recognition of both facial and vocal emotional signals. **Behaviour & Emotion recognition**: It is plausible that impairments in emotion processing and theory of mind might contribute or underpin changes of personality and social behaviour observed in bvFTD. However, this association was not explicitly tested.
8	Kipps, et al. (2009a) UK	FTD, n=14. Age (M=63.2, SD =8 years) DAT, n=14. Age (M=67.5, SD=9 years) 28 caregivers	Assess if the inability to appreciate emotions impacts on ability to perform activities of daily living (ADLs). Also investigated relationship between perception of emotions, neuropsychiatric features prominent in FTD and ADLs.	**Emotion & Social Cognition Measures:** The Emotion Hexagon (Calder et al., 1996a). **Behaviour Measures**: CBI. **Cognition Measures**: DAD, ACE-R, CDR.	FTD were found to be worse than DAT and controls at recognising emotions, particularly negative. FTD were also worse on ADLs compared to DAT. There was no strong association between ADLs and emotion recognition abilities. DAT were also significantly worse than controls at recognising emotions. **Behaviour & Emotion recognition**: There were significant correlations between mood ratings in CBI and emotion recognition abilities in FTD..

9	Kipps, et al. (2009b) UK	FTDp, n=12. Age (M=62.1, SD= 6.6) FTDc, n=14. Age (M=62.4, SD= 7.7) DAT, n=9. Age (M=69.0, SD= 6.9) Control, n=16. Age (M=66.4, SD= 4.9)	The aim of this study was to investigate whether FTD patients with behavioural problems would have deficits in the processing of dynamic emotional interactions and whether this would be correlated with impaired performance in the sarcasm task. The study also aimed to investigate whether atrophy in the orbitofrontal cortex, would be associated with this deficit.	**Emotion & Social Cognition Measures:** TASIT (Part I). **Behaviour Measures**: NPI, CBI. **Cognition Measures**: CDR, MMSE, ACE	**Behaviour & Emotion recognition**: Behavioural scores on the NPI and CBI did not differ between the DAT and FTD groups, although the scores were higher for the FTD group. The behavioural profile was also different for the FTD and DAT groups. There was a marked impairment in the ability of FTDp patients to recognize sarcastic, but not sincere statements and identify negative emotion compared to FTDc, DAT and controls.
10	Rankin, et al. (2009) USA	FTD, n=14. Age bvFTD, n=20. Age (M=60, SD= 8.1) SemD, n=11. Age (M=63.0, SD=8.6) PNFA, n=4. Age (M=66.3, SD= 11.5) DAT, n=27. Age (M=59.2, SD= 7.0) CBD, n=6.Age (M=67, SD= 6.2) PSP, n=9.Age (M=66.3, SD= 10.3) Controls, n=13. Age (M=61.8, SD= 10.3)	Investigate neuro-anatomic correlates in the ability to use paralinguistic cues to recognize sarcasm in participants with neurodegenerative diseases and determine the degree to which regional differences in brain volumes correspond to the ability to detect sarcasm from dynamic vocal and facial paralinguistic cues.	**Emotion & Social Cognition Measures:** TASIT (Part I & II), CATS. **Behaviour Measures**: NPI. **Mood Measures**: GDS. **Cognition Measures**: BNT, FAS, category fluency, Modified Rey-O Figure, WAIS-III, CVLT, WMS-III, Modified trails, Design Fluency, Stroop Interference, MMSE.	**Behaviour & Emotion recognition**: Patients were grouped into 'Pass' or 'Fail' (4 bvFTD, 8SemD, 2ADs and 1PSP) groups. 'Fail' group performed significantly worse that the 'Pass' group on tests of dynamic emotion recognition, confrontation naming, semantic fluency and verbal recognition memory, and they showed a significantly more impaired neuropsychiatric profile on the NPI. The '*Fail*' group performed significantly better on tests of visuo-spatial functioning, verbal and non-verbal working memory and inhibition tasks.

11	Shany-Ur, et. Al (2012) USA	bvFTD, n=39. Age (M=61.6, SD= 7.3) DAT, n=32. Age (M=62.3, SD= 9.1) PSP, n=16. Age (M=66.9, SD= 5.1) VD, n=15. Age (M=75.9, SD= 97) Controls, n=77. Age (M=68.2, SD= 8.9)	Examined the ability to comprehend lies and sarcasm from a third-person perspective, using contextual cues in 102 participants with neurodegenerative diseases and 77 healthy adult controls.	**Emotion & Social Cognition Measures:** TASIT, CATS. **Behaviour Measures**: NPI, IRI. **Mood Measures**: GDS. **Cognition Measures**: MMSE, BNT, Stroop Colour Naming, Trail Making Task, Benson Figure copy, CVLT	All participants equally understood sincere remarks, but bvFTD displayed impaired comprehension of lies and sarcasm on the. In other groups, impairment was not disease-specific but was proportionate to general cognitive impairment. **Behaviour & Emotion recognition**: Test performance on TASIT in bvFTD correlated highly with informant's ratings of participants' empathy, perspective taking and NPI scores (e.g. agitation).
12	Shimokawa, et al. (2001) Hon Kong	DAT, n=38. Age (M=79.5, SD= 6.3)	Investigate the relationship between poor interpersonal 42 behaviour and deteriorating emotion recognition ability in DAT patients.	**Emotion & Social Cognition Measures:** Emotion Recognition Test (Shimokawa et al., 2001). **Behaviour Measures**: IBC **Cognition Measures**: MMSE.	No significant correlation was found between MMSE and the Interpersonal Behaviour Scale. **Behaviour & Emotion recognition**: Significant correlations were found between IBC and ERT.
13	Sturm & Levenson (2011) USA	FTD, n=5. Age (M=66.2, SD= 5.0) SemD, n=4. Age (M=62.8, SD= 7.4) DAT, n=8. Age (M=60.5, SD= 6.6) CBD/PSP, n=8. Age (M=64.1, SD= 5.4) Control, n=7. Age (M=56.0, SD= 18.4)	Hypothesised that patients would have higher levels of alexithymia than controls. Also investigated the behavioural and neural correlates of alexithymia, predicting that alexithymia would be related to higher levels of behavioural disturbance and smaller Anterior Cingulate Cortex Gray matter volumes.	**Emotion & Social Cognition Measures:** Toronto Alexithymia Scale-20 (Bagby, Parker & Taylor, 1994). **Behaviour Measures**: NPI. **Cognition Measures**: MMSE, CDR	Alexithymia was common in participants with neurodegenerative conditions. FTD patients had the highest alexithymia scores. **Behaviour & Emotion recognition**: Higher levels of alexythimia were related with greater behavioural disturbance in participant's everyday lives.

Note.
Diagnosis:
DAT: Alzheimer's disease; ALS: Amyotrophic Lateral Sclerosis; CBD: Cortico-Basal Degeneration; FTD: Frontotemporal Dementia; FTDp: Frontotemporal Dementia with Structural Imaging Changes; FTDc: Frontotemporal Dementia without Structural Imaging Changes; bvFTD: Frontal Variant Frontotemporal Dementia; SemD: Semantic Dementia; PNFA: Progressive Non-Fluent Aphasia; PSP: Progressive Supranuclear Palsy; TBI: Traumatic Brain Injury.

Measures:
Behaviour Measures
CBI: Cambridge Behaviour Inventory (Bozeat et al., 2000); DEX: Dysexecutive Questionnaire (Wilson, Alderman, Burgess, Emslie, & Evans, 1996); ELQ: Emotional Liability Questionnaire (Newsom-Davis et al., 1999); FrSBe: Frontal Systems Behavioural Scale (Grace & Maloy, 2001); KAS-R: Katz Adjustment Scale revised (Goran & Fabiano, 1993); IBC: Interpersonal Behaviour Checklist (Shimokawa et al., 2001); IGT: Iowa Gambling Test (Bechara, Tranel & Damasio, 2000); IRI: Interpersonal Reactivity Index (Davis, 1980); MBQ: Manchester Behavior Questionnaire (Bathgate et al., 2001); NBAP: Neuropsychology Behaviour and Affect Profile (Nelson et al., 1998); NPI: Neuropsychiatric Inventory (Cummings et al., 1997); SIQ: Social Integration Questionnaire (Willer, Ottenbacher & Coad's, 1994).

Emotion Recognition and Social Cognition Measures
BFRT: Benton Facial Recognition Test (Benton et al., 1983); CATS: Comprehensive Affect Testing System (Froming et al., 2001); EFRT: Ekman Face Recognition Test (Ekman and Friesen, 1976); EEQ: Emotional Empathy Questionnaire (Mehrabian and Epstein, 1972); FAB: Florida Affect Battery (Bowers, Blonder & Heilman, 1991); Faux Pass Test (Stone et al., 1998); FEEST: Facial Expression of Emotion Stimuli and Test (Young et al., 2002); TASIT: The of Awareness and Social Inference Test (McDonald, 2003); TAS-20: Toronto Alexithymia Scale-20 (Bagby, Parker & Taylor, 1994)

Cognition
ACE: Adenbrooke's Cognitive Examination (Mathuranath et al., 2000); ACE-R: Addenbrooke's Cognitive Examination Revised (Mioshi et al., 2006); AFT: Alternating Fluency Test (Downes et al., 1993); BNT: Boston Naming Test (Kaplan, 1983); BSAT: Brixton Spatial Anticipation Test (Burgess & Shallice, 1997); CDR: Cognitive Dementia Rating (Morris, 1997); CVLT: California Verbal Learning Task (Delis et al., 1987); DAD: Disability Assessment of Dementia (Gelindas et al., 1999); FAS: Letter Fluency Test; GNT: Graded Naming Test (McKenna & Warrington, 1983); KOLT: Kendrick Object Learning Task (Kendrik, 1985); MMSE: Mini Mental State Examination (Folstein, Folstein & McHugh, 1975); NART-R: National Adult Reading Test- Revised (Crawford, 1990); RFFT: Ruff Figural Fluency Test (Ruff, 1996); UFO: Uses for Objects (Crawford, Wright & Bate, 1995); WAIS-III: Weschler Adult Intelligence Test, 3rd Ed (1997); WCST: Wisconsin Card Sorting Test (Berg, 1948); WMS-R: Weschler Memory Scale Revised (1981); WMS-III: Weschler Memory Scale 3rd Ed. (2003).

Mood
FAB: Florida Affect Battery (Bowers et al., 1998); GDS: Geriatric Depression Scale (Yesavage et al., 1983); HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

Author, Date, Country	1	2	3	4	5	6	7	8	9	10	11	12	Quality Rating
Milders, et al. (2008), UK	AA (++)	WC (+++)	AA (++)	WC (+++)	WC (+++)	NA (0)	WC (+++)	NA (0)	NA (0)	NA (0)	NA (0)	AA (++)	18
Gregory, et al. (2002), UK	WC (+++)	AA (++)	PA (+)	PA (+)	WC (+++)	NA (0)	AA (++)	NA (0)	PA (+)	PA (+)	PA (+)	AA (++)	17
Milders, et al. (2003), UK	WC (+++)	WC (+++)	AA (++)	WC (+++)	NA (0)	NA (0)	WC (+++)	NA (0)	NA (0)	NA (0)	NA (0)	WC (+++)	17
Rankin, et al. (2009), USA	PA (+)	WC (+++)	AA (++)	AA (++)	WC (+++)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	AA (++)	AA (++)	17
Shimokawa, et al., (2001), Hon Kong	AA (++)	WC (+++)	AA (++)	NA (0)	WC (+++)	NA (0)	AA (++)	NA (0)	WC (+++)	PA (+)	NA (0)	PA (+)	17
Shany-Ur, et al. (2012), USA	WC (+++)	WC (+++)	AA (++)	PA (+)	WC (+++)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	AA (++)	16
Kipps, et al. (2009b), UK	WC (+++)	PA (+)	AA (++)	AA (++)	PA (+)	NA (0)	WC (+++)	NA (0)	NA (0)	NA (0)	NA (0)	PA (+)	13
Kipps, et al. (2009a), UK	WC (+++)	PA (+)	AA (++)	AA (++)	NA (0)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	AA (++)	12
Girardi, et al. (2011a), UK	AA (++)	AA (++)	PA (+)	AA (++)	AA (++)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	PA (+)	12
Girardi, et al. (2011b), UK	AA (++)	AA (++)	PA (+)	AA (++)	AA (++)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	PA (+)	12
Keane, et al. (2002), UK	WC (+++)	PA (+)	PA (+)	PA (+)	AA (++)	NA (0)	WC (+++)	NA (0)	NA (0)	NA (0)	NA (0)	PA (+)	12
Sturm & Levenson (2011), USA	AA (++)	AA (++)	PA (+)	AA (++)	PA (+)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	AA (++)	12
Hornak, et al. (1996), UK	AA (++)	AA (++)	NA (0)	PA (+)	NA (0)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	NA (0)	PA (+)	8

Table 2.3. *Quality Assessment of Original Research*

Note. Quality Assessment

1. The rationale for investigating emotion identification and behavioural difficulties in stroke, brain injury or neurodegenerative conditions is clearly discussed.
2. The sample is well described.
3. Caution has been taken to make sure that the sample is representative of the population.
4. When a control group is used, they should be matched in all aspects other than the factors under investigation.
5. An internationally recognised classification system should be used for individuals included in the research who are identified as having a stroke, a brain injury or a neurodegenerative condition.
6. The study indicates how many of the participants in each group who were asked to take part in the study actually managed to complete each or all measures, i.e. it gives an indication of missing data.
7. The study gives a rationale for the choice of tests employed.
8. Attrition rates are reported for each of the groups studied.
9. Reliability and validity are reported for the emotion identification measure.
10. Reliability and validity are reported for assessments looking at individual's behaviour.
11. Statistical power of the study is addressed.
12. Generalisability of the findings is discussed, as well as implications and limitations of the study.

Ratings: WC, well covered (+++); AA, adequately addressed (++); PA, poorly addressed (+); NA, not addressed (0); NAA, not applicable (0).

2.4.3 Characteristics of the Included Studies

Of the 13 included studies, one was a case series of six individuals with bvFTD, whilst the remaining 12 studies were cross-sectional designs.

2.4.3.1 Aims of the Included Studies

Of the 13 studies selected, one study (Sturm & Levenson, 2011) assessed the individual's ability to assess their own emotions (i.e. alexithymia) while the remaining 12 studies assessed the individual's ability to recognise others' emotions or other aspects of social cognition. Alexythimia has been suggested as part of social cognition (Bird, 2013) and thus was included in this review. Nine of the studies (Girardi et al., 2011a, b; Hornak, et al., 1996; Kipps et al., 2009a; Milders et al., 2003, 2008; Shany-Ur et al., 2012; Shimokawa et al., 2001; Sturm & Levenson, 2011) explicitly investigated the links between an individual's ability to recognise emotions and their own behaviour. For two of the studies (Keane et al., 2002, Kipps et al., 2009b) the relationship between emotion identification and behaviour changes was not explicitly assessed and for one study, this was a secondary aims (Rankin et al., 2009). A study by Gregory and colleagues (2002) used several ToM tasks, Reading the Mind in the Eyes Test (Baron-Cohen et al., 1997), First and Second Order False Belief Test (Wimmer, 1985; Baron Cohen, 1989) and the Faux Pas Test (Stone et al., 1998; Baron-Cohen et al., 1999a). Their study related participants' performance to behaviour and neuropsychiatric changes. Moreover, the study by Girardi and colleagues (2011a) used an affective decision making task. This was a modified version of the Iowa Gambling Task and linked participants' performance in this task to behaviour changes in non-demented ALS participants. Although not a social cognition measure per se, the IGT is strongly linked to an individual's

affective decision making abilities and perseveration, usually associated with orbitofrontal damage (Elamin et al., 2012).

2.4.3.2 Participant Samples

Recruitment of a comparison or control sample varied between the studies. Two studies (Keane et al., 2002; Shimokawa et al., 2001) did not use control or comparison groups. In addition, one study (Hornak, et al., 1996) recruited participants who experienced a stroke without damage to the ventromedial region of the frontal lobes as a comparison group, while another study (Milders et al., 2008) used orthopaedic controls. The remaining nine studies used healthy adult controls. Three studies did not report how controls were recruited (Kipps et al., 2009 a,b, Sturm et al., 2011). Three studies recruited from a volunteer panel (Girardi et al., 2011 a,b; Gregory et al., 2002), two through advertisements at the local newspaper (Rankin et al., 2009, Shany-Ur et al., 2012) and one study recruited both via a volunteer panel and the local newspaper (Milders et al., 2003). Kipps et al. (2009a, 2009b) and Sturm et al. (2011) did not report gender in their studies. The remaining ten studies showed a bias towards male participants (Table 2.4). Only two studies (i.e. Shimokawa et al., 2001; Rankin et al., 2009), both including populations with neurodegenerative conditions, were biased towards female participants.

With the exception of Shimokawa et al. (2001) and the PNFA, PSP, CBD and DAT subgroups in Rankin et al. (2002) study, the remaining studies showed a higher percentage of male than female participants in their samples. However, as Ruitenberg et al. (2001) suggest there appear to be no gender differences in the incidence of DAT up to a high age. It is only after 90 years of age that significant differences in gender emerge, with females more likely than males to develop DAT.

Furthermore, Ruitenberg and colleagues (2001) found that males had a higher incidence than females to develop vascular dementia in all age groups. In order to get a representative population it is important to take gender differences into consideration. Future studies should attempt to include more female participants into their research in order to make data more representative and results more generalisable.

Three studies (Hornak, et al., 1996; Milders, et al., 2003, 2008) recruited participants who had suffered a TBI or stroke. Only Milders and colleagues (2003, 2008) gave an indication of Post-Traumatic Amnesia (PTA) and Glasgow Coma Scale (GCS) mean scores for TBI participants and classified them according to Teasdale and Jennett (1974) conventional classification system for TBI as mild, moderate or severe.

For the remaining ten studies, one study assessed individuals with DAT (Shimokawa et al., 2001), one study assessed individuals with FTD (Keane et al., 2002), two studies assessed individuals with ALS (Girardi et al., 2011), three studies assessed both individuals with FTD and DAT (Gregory et al., 2002; Kipps et al., 2009a, b), and three studies (Rankin et al., 2009; Shany-Ur et al., 2012; Sturm & Levenson, 2011) assessed a variety of participants with diverse neurodegenerative presentations including, DAT, FTD, SemD, PNFA, PSPS, CBD.

Five studies (Kipps et al., 2009a, b; Rankin et al., 2009; Shany-Ur et al., 2012; Sturm & Levenson, 2011) used the Clinical Dementia Rating Scale (Morris, 1993) to classify individuals into mild, moderate or severe stages.

Table 2.4. *Number of Males and Females in Each Study.*

	Participant Group		Control Group	
Study	**Males**	**Females**	**Males**	**Females**
Studies with Participants with TBI or Stroke				
Hornak, et al. (1996)	10 TBI/Stroke	2 TBI/ Stroke	9	2
Milders et al. (2003)	10 TBI	7 TBI	10	7
Milders et al. (2008)	28 TBI	5 TBI	30	4
Studies with Participants with Neurodegenerative Conditions				
Girardi et al. (2011a)	12 ALS	7 ALS	9	11
Girardi et al. (2011b)	10 ALS	4 ALS	15	5
Gregory et al. (2002)	16 FTD 6 DAT	3 FTD 6 DAT	8	8
Keane et al. (2002)	6bvFTD	0	NA	NA
Kipps et al. (2009a)	—	—	—	—
Kipps et al. (2009b)	—	—	—	—
Rankin et al. (2009)	15 bvFTD 5 SemD 0 PNFA 16 DAT 0 CBD 2 PSP	5 bvFTD 6 SemD 4 PNFA 11 DAT 6 CBD 7 PSP	5	8
Shany-Ur et al. (2012)	26 bvFTD 17 DAT 8 PSP 6 VD	13 bvFTD 15 DAT 8 PSP 9 VD	32	45
Shimokawa et al. (2001)	12 DAT	26 DAT	NA	NA
Sturm et al. (2011)	—	—	—	—

Note. DAT: Alzheimer's disease; ALS: Amyotrophic Lateral Sclerosis; CBD: Cortico-Basal Degeneration**;** FTD: Frontotemporal Dementia**;** SemD: Semantic Dementia**;** PNFA: Progressive Non-Fluent Aphasia**;** PSP: Progressive Supranuclear Palsy**;** TBI: Traumatic Brain Injury. Kipps et al. (2009a, 2009b) and Sturm et al. (2011) do not report male/female ratio**.**

2.4.3.3 Emotion Recognition and Social Cognition Measures

Measures used to assess social cognition were varied and included the Benton Facial Recognition Test (BFRT, Benton et al., 1983), the Comprehensive Affect Testing System (CATS, Froming et al., 2001), the Cartoon Test (Happé et al., 1999), the Ekman Face Recognition Test (EFRT, Ekman & Friesen, 1976), the Emotional Empathy Questionnaire (EEQ, Mehrabian & Epstein, 1972), the Emotion Hexagon (Calder et al., 1996a), the Emotion Recognition Test (Shimokawa et al., 2001), the Faux Pass Test (Stone et al., 1998), the Facial Expression of Emotion Stimuli and Test (FEEST, Young et al., 2002), the Famous Faces Recognition Test (Keane et al., 2002), the Gaze Processing Test (Keane et al., 2002), the Iowa Gambling Test (IGT, Bechara, Tranel & Damasio, 2000), the Judgment of Preference Task (E-Prime Task, from Baron-Cohen et al., 1995 and Snowden et al., 2003), the Reading the Mind in the Eye Test (Baron-Cohen et al., 1997), the Recognition of Vocal Emotions (Keane et al., 2002), the of Awareness and Social Inference Test (TASIT, McDonald, 2003) or the Toronto Alexithymia Scale-20 (Bagby, Parker & Taylor, 1994). Four studies used the EFRT and three studies used the TASIT to assess social cognition. However, there appeared to be no consistent measure used by all studies to assess this ability.

With regard to the reliability and validity of the measures used, Gregory et al. (2002) described the social cognition tasks used and made reference to aspects of reliability and validity of the measures used. The study by Shimokawa et al. (2001) covered in detail the reliability and validity aspects of one of the measures used in the study (the Emotion Recognition Test, ERT), however this was not the case for the other measures used in the study. Most studies did not describe the reliability and validity of the emotion recognition and social cognition measures used.

2.4.3.4 Behaviour Measures

Behavioural assessment was conducted using a wide range of measures including the Cambridge Behaviour Inventory (CBI, Bozeat et al., 2000), the Dysexecutive Questionnaire (DEX, Wilson et al., 1996), the Emotional Lability Questionnaire (ELQ, Newsom-Davis et al., 1999), the Frontal Systems Behavioural Scale (FrSBe, Grace & Maloy, 2001), Interpersonal Reactivity Index (IRI, Davis, 1980); the Katz Adjustment Scale revised (KAS-R, Goran & Fabiano, 1993), the Interpersonal Behaviour Checklist (Shimokawa et al., 2001), the Manchester Behaviour Questionnaire (MBQ, Bathgate et al., 2001), Neuropsychology Behaviour and Affect Profile (NBAP, Nelson et al., 1998), the Neuropsychiatric Inventory (NPI, Cummings et al., 1997), Social Integration Questionnaire (SIQ, Willer, Ottenbacher, & Coad's, 1994), the Subjective Emotional Change Questionnaire (Hornak, et al., 1996) and the Staff Behaviour Questionnaire (Hornak, et al., 1996). Six studies used the NPI (Cummings et al., 1997) to assess changes in behaviour. Nine of the studies asked partners or home carers to rate the individual's behaviour. Two studies used ward staff and three studies used self-monitoring questionnaires together with questionnaires given to carers or partners to assess an individual's behaviour change. Six studies used more than one measure to assess behaviour.

Regarding reliability and validity issues relating to the behavioural measures used, only two studies (Gregory et al. 2002; Shimokawa et al. 2001) made reference to some aspects of reliability and validity. Considering that description of behaviour that challenges is usually a subjective phenomenon based on the eye of the beholder, reliability among behaviour measures should be carefully considered.

2.4.3.5 Additional Measures

For the three TBI or stroke studies included in this review, Milders et al. (2003, 2008) assessed length of Post-Traumatic Amnesia (PTA) and Glasgow Coma Scale for all patients, allowing them to categorise participants into mild, moderate and severe. No premorbid assessment measures were reported. Hornak et al. (1996) mentioned that all patients in their study received a full neuropsychological assessment, which placed them all within the average range for verbal IQ. No scores were reported by Hornak et al. (1996) study regarding either premorbid or neuropsychological profile assessments.

Of the remaining nine studies, only five (Kipps et al., 2009a, 2009b; Rankin et al., 2009; Shany-Ur et al., 2012; Sturm et al., 2011), reported Clinical Dementia Rating (CDR) and MMSE scores for their participant samples. The CDR assesses memory, orientation, judgment & problem solving, community affairs, home & hobbies, and personal care. Scores on the CDR for all four studies indicate participants with neurodegenerative conditions show mild difficulties in these domains. Shimokawa et al. (2001) only used the MMSE to determine severity of difficulties. Gregory et al. (2002), Keane et al. (2002) and Girardi et al. (2011a) all report premorbid assessment scores, (NART scores), for patients and controls. In addition to premorbid scores, Gregory et al. (2002) and Keane et al. (2002) also report MMSE scores for their participant samples. Girardi et al. (2011b) does not appear to report premorbid cognitive ability or MMSE scores, however an in depth neuropsychological assessment was carried out with patients in this study and scores reported.

2.4.3.6 Attrition, Missing Data, Sample Sizes and Power

Bezeau and Graves (2001) recommended that *apriori* power analyses should always be calculated in neuropsychological research. However, none of the 13 studies included did not report *a priori* statistical power calculations or sample estimates. Power analysis can be used to calculate the sample size required for a study to be able to detect an effect of a given size (Field, 2009). However, many neuropsychology studies fail to report power, making it difficult to critically interpret results from these and leading to biased estimates of effect sizes (Maxwell, 2004). It appears that some of the studies attempted to overcome the relatively small number of patients in some of the rarer neurodegenerative conditions by amalgamating results and grouping participants into those who had '*passed'* or '*failed'* the cognitive tests (e.g. Rankin et al., 2009). Caution should be taken when interpreting results from these studies as different conditions may show differing degrees of impairments in different social cognition abilities and even different behaviour change patterns (Bathgate et al., 2001). This in turn will affect how generalisable the results of the study are.

No indication was given of number of participants initially approached and number of participants who agreed to participate. No indication was given of missing data for each of the assessments used. Only four studies gave an indication of effect sizes, making it difficult to compare across studies. Effect sizes ranged from large (Girardi et al., 2011a, Gregory et al., 2002; Kipps et al., 2009b) to medium or small (Shany Ur et al., 2012; Sturm et al., 2011). Seven of the included studies used a table to indicate the scores of individuals on some of the tests included and from these it was possible to determine some of the missing data; however when a score of 0 was given to a participant, no explanation was given as to whether the participant attempted the task and scored 0 or they were unable to complete the task.

2.4.4 Summary of the Main Findings

2.4.4.1 Stroke and TBI Samples

Three studies were selected under this category. All studies were cross-sectional observational studies. None of the studies included found a correlation between emotion recognition difficulties and proxy-ratings of behaviour change. Hornak and colleagues' (1996) study was rated the lowest with regards to quality criteria. Quality ratings regarding representativeness of clinical sample as well as psychometric evaluations of social cognition and behaviour measures used were found to be 'poorly addressed' or 'not addressed'. As such, this section of the review will focus on both Milders et al. (2008) and (2003) studies, both of which were rated highly (18/36 and 17/36 respectively)in the present study.

Milders and colleagues (2003) found that individuals with a TBI showed more problems in emotional and social behaviour following brain injury. The study also reported that the patient group were impaired in tasks of recognition of emotional expressions in the face and the voice. However, Pearson's correlations revealed no significant association between increased behavioural problems and emotion recognition difficulties. Milders and colleagues (2008) found that individuals with TBI showed significant difficulties in tests of emotion recognition, theory of mind and cognitive flexibility compared to a control orthopaedic group. In addition, Milders et al. (2008) showed an increase in behavioural problems one-year post injury, as measured by their carers. However, Pearson's correlations failed to find an association between proxy ratings of behaviour and emotion recognition difficulties.

2.4.4.2 Neurodegenerative Conditions Samples

Ten studies were selected under this category. One study (Keane et al., 2002) was a case series of six people with a clinical diagnosis of bvFTD. The remaining nine studies were cross-sectional observational studies.

Two studies (Keane et al., 2002; Kipps et al., 2009b) did not explicitly investigate the relationship between emotion recognition and behavioural changes, despite measuring both constructs. Clinical judgement was applied and a decision was reached to include these studies as they both suggest a possible link between social cognition and behaviour, as well as measure both constructs. Authors of the studies were approached, without success. Both studies were rated poorly with regards to reporting of attrition, missing data, power, reliability and validity issues of the samples include. As such, although both studies suggest a neuroanatomical link in individuals with a diagnosis of bvFTD with regards to social cognition and behaviour, these two constructs were not explicitly correlated and the low quality ratings highlight that results of these studies should be interpreted with caution.

The remaining eight studies (Girardi et al., 2011 a, b: Gregory et al., 2002; Kipps et al., 2009a; Rankin et al., 2009; Shany-Ur et al., 2012; Shimokawa et al., 2001; Sturm & Levenson, 2011) all found significant correlations between social cognition and behaviour change. Of these, four (Gregory et al., 2002; Rankin et al., 2009; Shany-Ur et al., 2012; Shimokawa et al., 2001) were rated higher (above 16/36) with regard to quality ratings. One of these studies (Rankin et al., 2009) attempted to overcome issues regarding small sample sizes by recruitment of several different clinical populations and categorising sample, not by clinical presentation, but rather by whether they had ‘passed’ or ‘failed’ a task.

A study by Gregory et al. (2002), which received the highest rating within the inclusion of neurodegenerative clinical population, assessed ToM. Their study aims were twofold: firstly they aimed to assess ToM in individuals with bvFTD and DAT and secondly, they explored the relationship between performance on tests of ToM, traditional frontal executive tasks and the degree of neuropsychiatric and behavioural dysfunction shown in participants with bvFTD and DAT. Gregory et al., (2002) study's strengths lie, particularly, on the study's extensive social cognition battery and the use of a psychometrically reliable and valid behaviour measure. Its main limitation relates to a failure to report attrition or missing data, which can potentially confound the association found between NPI and all three ToM tasks for individuals with bvFTD.

Rankin and colleagues (2009) investigated the neuro-anatomic correlates of the ability to use paralinguistic cues to recognise sarcasm in participants with neurodegenerative conditions and aimed to determine the degree to which regional differences in brain volumes corresponded to the ability to detect sarcasm from dynamic vocal and facial paralinguistic cues. A strength within Rankin et al.'s (2009) study related to the comparison of means of the '*fail'* and '*pass'* groups. This method of categorising participants overcame potential issues of power by selecting a wider range of participants. Rankin et al (2009) found that individuals who were considered to have '*failed'* the detection of sarcasm test, also performed significantly worse on tests of dynamic emotion recognition and showed a significantly more impaired neuropsychiatric profile on the NPI. This study supported the link between difficulties identifying emotions and behavioural changes in neurodegenerative conditions.

Shimokawa et al. (2001) explored the statistical relationship between social cognition measures, i.e. the ERT, and interpersonal behaviour changes as assessed by the IBC. Shimokawa et al. (2001) found that both behaviour components of the IBC scale '*indifference to interpersonal relationships*' and '*difficulty in treatment management*' in their DAT participant sample, correlated significantly with the ERT score. In addition they used the MMSE as a scale of intellectual performance and found that neither behaviour nor emotion recognition scores were significantly correlated with MMSE performance. These results led them to suggest that the behaviour of patients with DAT does not depend on deterioration of cognitive ability but rather on a decreased ability for emotion comprehension (Shimokawa et al., 2001). A particular strength in this study relates to its detailed description of the included sample and the social cognition measure used.

Shany-Ur et al. (2012) assessed social cognition using the TASIT in individuals with bvFTD, DAT, VD and PSP. The links between social cognition and behaviour however were only assessed in bvFTD. The study found that TASIT performance correlated with informants' ratings of participant's empathy, perspective taking and neuropsychiatric symptoms in everyday life as measured by the IRI and NPI.

Kipps and colleagues (2009a) investigated the relationship between emotion, apathy and other neuropsychiatric symptoms and measures of social competence such as Activities of Daily Living (ADLs) performance in individuals with FTD and a matched comparison group of patients with DAT. Non-parametric tests were used to assess the level of association between the three main variables, social cognition, behaviour and ADLs. Their study found significant correlation between the CBI mood subscores and performance on the emotion recognition task in individuals with

FTD. Due to insufficient numbers in both the emotion and behavioural measures for the DAT group, the researchers did not look at correlations in this population. The study concluded that the presence of greater emotional reactivity in FTD patients predicted a better ability to recognise emotional states in others.

Sturm and Levenson (2011) assessed alexithymia in individuals with a neurodegenerative condition and healthy controls and its association to behavioural change and smaller anterior cingulate cortex gray matter volumes. Results showed significant correlations between total NPI scores and alexithymia. More specifically, the apathy and carers distress subscales of the NPI were highly correlated with total alexithymia scores.

Finally, Girardi and colleagues (2011) published an article on the deficits in emotional and social cognition in ALS, which included two separate studies. The first study investigated the performance of non-demented ALS participants on a social cognition and decision-making task, the IGT, as well as the relationship with behavioural change, measured using the FrSBe. Results from the first study showed that non-demented ALS participants had difficulties with the IGT task. In addition, poorer performance on the IGT task was significantly related to overall level of behavioural dysfunction in daily life.

The second study by Girardi et al. (2011b) aimed to undertake a more in-depth analysis of social and emotional cognition in ALS patients. Participants' behaviour was assessed using the MBQ, CBI and FrSBe, while social and emotional cognition was assessed using the Judgment of Preference Task, the Reading the mind in the Eyes test and the FEEST. A significant proportion of non-demented ALS was impaired when asked to infer others' mental states. In addition, 10 out of 14 ALS participants showed changes in their behaviour, as rated by their carers using the

MBQ and CBI. The presence of behaviour change strongly overlapped with social cognition difficulties, with 5 patients (36 per cent) showing difficulties on the Judgment of Preference task and behaviour change.

2.5. Discussion

Several studies have shown that individuals with ABI or neurodegenerative conditions, may have significant difficulties in social cognition measures such as recognising emotions as expressed in the face, the voice or body posture (Croker & McDonald, 2005) or impaired performance in ToM tests (Gregory et al., 2002; Milders et al., 2003; 2006). Similar results have also been shown in individuals with neurodegenerative conditions, particularly in individuals with a diagnosis of FTD. A dichotomy between ABI and neurodegenerative conditions appears to have emerged with regards to the existence of a possible link between social cognition and behaviour. Four moderately high quality rated studies appear to suggest a relationship between behavioural changes, such as lack of empathy, which are commonly reported following brain damage or neurodegeneration (Lough et al., 2006; Neary et al., 1998; Rankin, Kramer & Miller, 2005) and significant social cognition difficulties, such as recognising others' emotions (Kipps et al., 2009a). However this is not the case for studies including ABI clinical populations,

Variations in sample size, aetiology, behaviour or social cognition measures used, cognitive ability, family coping mechanisms and ability to manage behaviour changes make comparisons across studies difficult and may account for some of the mixed results found in studies with participants with neurodegenerative conditions. It is however possible that the distinction in the presence of this link between both

samples is due to the specificity of of lesion common in ABI samples. Neurodegeneration encompasses a wider degree of impairments across different regions of the brain; it is thus possible that social cognition abilities, although prominent in the prefrontal cortex (Beer et al., 2006), may be related to other neuroanatomical pathways and regions within the brain, such as the limbic system, and in particular the amygdala (Adolphs, 2001). These regions are readily affected in the process of neurodegeneration, whilst this may not be the case in localised brain lesions such as TBI.

2.5.1 Limitations of the Literature and Directions for Future Research

Although this systematic review has identified some support for the potential link between social cognition and behaviour changes, conclusive results cannot be established due to a number of methodological difficulties within the reviewed literature. These limitations as well as recommendations for future research are discussed.

2.5.1.1 Studies Explicitly investigating Behaviour and Social Cognition

The present review highlights the scarcity of studies explicitly assessing the relationship between behaviour change and social cognition following ABI or onset of a neurodegenerative condition. Only eleven of the thirteen studies in this review explicitly assessed the association between behaviour change and social cognition, with one of these studies assessing an individual's ability to recognise one's own emotions rather than others. Of the eleven studies that explored this association, only 6 rated higher than 16/36 on the quality assessment, indicating significant methodological issues in the study of social cognition and behaviour in neurological

populations. In addition, as this review has pointed out, social cognition and behaviour change are very general constructs that encompass different aspects within them, making comparisons across studies difficult.

2.5.2 Implications and Recommendations

As the present review highlights, further research is needed within the field of behaviour and social cognition. More specifically, studies should account for performance differences within various aetiologies and research should thus be more aligned to a particular population. This would allow studies to be more clinically relevant and could possibly guide behaviour management strategies and future interventions for those populations. At present the scarcity of results and methodological differences make it difficult to draw conclusive and generalisable results to reliably inform clinical practice.

Caregivers of people with dementia or ABI often have age related health problems themselves (Department of Health, 2009; Haley, Roth, Howard and Stafford, 2010), which can make the caring process very stressful. There is therefore a high prevalence of depression and physical illness amongst carers (Department of Health 2009, Vitaliano, Scanlon, & Zhang, 2003). When additional behavioural and psychological changes occur, this can be associated with increased caregiver burden and nursing home and hospital admissions (Burke & Morgenlander, 1999; Cohen et al., 1993; Hebert, Dubois, Wolfson, Chambers & Cohen, 2001). Consequently, studies assessing possible predictors of behaviour change in the context of neurodegenerative conditions or ABI, may provide caregivers and practitioners alike

some further understading of the links to behaviour changes and help manage these in day-to-day settings.

In addition, mood difficulties such as depression are frequent complications of ABI or neurodegenerative conditions and can hinder patients' rehabilitation and coping mechanisms (Aström, Adolfsson & Asplund, 1993; Jorge, Robinson, Moser et al., 2004; Korczyn & Halpern, 2009). Considering most psychological interventions rely on an individual´s ability to recognise their own and others' emotions, knowledge of possible impairments within the area of social cognition, such as poor emotion recognition skills, becomes vital in order to be able to adapt any psychotherapeutic intervention and decrease the disabling effect that low mood or anxiety may have in ABI or dementia populations. In addition, knowledge of possible associations between social cognition and behaviour changes is important in providing adequate patient-centred care and formulating behaviour difficulties adequately.

2.6. Conclusion

Establishing possible associations between social cognition and behaviour changes is important in order to further understand, better support and manage behaviour changes following ABI or onset of a neurodegenerative disease. Due to the limited number studies available assessing this link, the current review had a broad inclusion criteria allowing for studies that suggested a link or those that assessed both social cognition and behaviour, even when this link was not directly assessed. Only eleven of the studies tested both variables and their links. Of these, only six were rated above 16 on the quality assessment scale, indicating a general low methodological quality in studies assessing this link within neurological

populations. The included studies proved to have various methods for assessing each construct or relationship and several methodological issues have been highlighted, which significantly impact on the quality ratings for the included studies. As a result, it is not possible to draw conclusive evidence regarding the possible link between social cognition and behaviour change following ABI or onset of neurodegenerative conditions at present.

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3. Empirical Article:

Social Cognition in Dementia of the Alzheimer Type and Mixed Dementia and its Association with Behaviour and Relationship Quality as Reported by Partners

Running head: Social Cognition and Behaviour

Social Cognition in Dementia of the Alzheimer Type and Mixed Dementia and its Association with Behaviour and Relationship Quality as Reported by Partners

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This article followed the author's guidelines from the journal 'Journal of Clinical and Experimental Neuropsychology'. Tables have been kept in the corresponding position in text for ease of reading and correcting, but will be formatted according to guidelines before submission.

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Abstract

Social cognition can be impaired in a range of neurodegenerative conditions. This study assessed social cognition in 27 participants with Dementia of the Alzheimer Type (DAT) or mixed dementia and their co-residing partners (*n*=27) and explored the relationships between social cognition, cognitive ability, relationship quality and behaviour following diagnosis. Participants with DAT scored lower on social cognition tasks compared to their partners. Behaviour changes in participants with DAT were significantly related to relationship quality, however no significant associations were found with social cognition. The results of this study are discussed within a therapeutic context and in line with current guidelines and policies.

Keywords: Social cognition, Alzheimer's disease, dementia, Theory of Mind, emotion recognition.

3.1. Introduction

Everyday social exchanges can be very complex. People make jokes, talk sarcastically or may even intentionally lie (Harada et al., 1998). As a consequence, social adeptness requires a person to be able to correctly interpret these forms of speech and act accordingly (Keltner & Kring, 1998). An individual's ability to understand a speaker's intention relies on their skilful integration of semantic, syntactic, contextual and paralinguistic information as well as on their pragmatic knowledge and ability to take visual perspectives, understand emotions and utilise theory of mind (ToM) (Shany-Ur et al., 2012). Collectively, these skills are known as social cognition (Fiske & Taylor, 2008).

Initial research into social cognition mainly focused on ToM, an individual's ability to attribute mental states and interpret others' behaviour according to those mental states (Baron-Cohen, Leslie, & Frith, 1985). ToM was primarily studied in individuals who presented with social skills difficulties, such as people on the autistic spectrum or with damage to their frontal lobes (Elamin, Pender, Hardiman & Abrahams, 2012). Evidence of deficits in ToM in individuals with autism revolutionised the way in which researchers understood neurodevelopmental disorders and stimulated interest into the neurocognitive architecture of ToM (Tager-Flusberg, 2007). Neuroanatomical research into social cognition with individuals following a traumatic brain injury (TBI), particularly those with right frontal damage who showed significant deficits in ToM skills, suggested the possibility of a complex fronto-striatal network with likely right hemispheric dominance subserving social cognition functions in the brain (Abu-Akel & Shamy-Tsoory, 2011). This area can also be affected in other neurological conditions, such as neurodegenerative

conditions or stroke.

With an ageing population and improvements in mortality rates at the oldest ages (Office of National Statistics, 2012), there is an increasing drive to investigate conditions typically associated with older age, such as dementia (Department of Health [DoH], 2009). In addition, considering the progressive pathological nature of neurodegenerative conditions, the study of social cognition in dementia may clarify some of the mechanisms underlying why some individuals show impaired social comprehension and changes in their interpersonal behaviour (Elamin et al., 2012; McKhann et al., 2001) and may help with longitudinal disease tracking (Kipps, Nestor, Acosta-Carbonero, Arnold & Hodges, 2009), or by providing tailored psycho-education to patient, carers and families regarding managing these difficulties.

Most research in social cognition and dementia has focused on frontotemporal dementia (FTD), with a particular interest in the behavioural variant of frontotemporal dementia (bvFTD), in an attempt to aid diagnosis of this condition (Elamin et al., 2012). The subdivision of FTD into bvFTD, semantic dementia (SD) and progressive non-fluent aphasia (NPFA) is however not widely accepted (Neary et al., 1998). As a consequence, the homogeneity of participants in FTD studies will depend on the diagnostic criteria used.

Individuals with bvFTD usually present with a significant decline in social and emotional comprehension and changes in behaviour suggestive of poor social cognition (Lavenu, Pasquier, Lebert, Petit & Van der Linden, 1999). Early stages of

bvFTD can be associated with normal imaging and preserved executive functioning skills, whilst presenting with significant interpersonal and behaviour changes (Piguet, Hornberger, Mioshi, & Hodges, 2011). As a result, a diagnosis of bvFTD is heavily reliant on carers' reports of behaviour, which can often be inconsistent, subjective and culturally biased (Elamin et al., 2012). As a way to overcome such diagnostic difficulties, researchers have proposed a role for formal neuropsychological assessment of social cognition in bvFTD (Elamin et al., 2012) and other neurodegenerative conditions presenting with behaviour or social changes.

The most commonly diagnosed neurodegenerative conditions are Dementia of the Alzheimer Type (DAT; Diagnostic and Statistical Manual of Mental Disorders, [DSM-V], 2013) and cerebrovascular dementia (VD; Román et al., 1993). Between them, they account for over 50 per cent of all dementia cases (Cummings & Benson, 1992). In addition, ten per cent of people with a neurodegenerative condition, receive a diagnosis of mixed dementia, meaning that both DAT and VD may be affecting the brain (Alzheimer's Society, 2011).

DAT appears to be most prominent in the posterior and medial cortex (McKhann et al., 1984; Seeley & Crawford, 1997). Consequently, individuals with a diagnosis of probable DAT will typically present with primarily cognitive symptoms such as difficulties with memory, language or visual and spatial functions (McKhann et al., 1984; Mendez et al., 1990). The global nature of DAT however, may entail frontal atrophy and degeneration of the brain later on in the course of the disease (Tikofsky, Hellman, & Parks, 1993). As a consequence, some individuals may also experience difficulties in their attention and executive functioning (Perry & Hodges,

1999) or can show behaviour and social cognition difficulties (McKhann et al., 1984; Seeley et al., 1997). In contrast, the pattern of impairments in VD is very variable. This is mainly due to the aetiology of this condition, varying from small vessel disease to haemorrhagic or ischemic stroke, which can affect any area of the brain (Román et al., 1993).

Research into social cognition in neurodegenerative conditions is still within its infancy, particularly for individuals with VD. Very few studies (e.g. Shimokawa et al., 1999, 2000) have assessed emotion recognition in VD. Shimokawa et al. (1999) assessed emotion recognition in a group of 25 individuals with VD and 25 with DAT and found that the VD group showed significant difficulties identifying static displays of human emotions, whereas there were no difficulties in identifying emotions in the DAT group. The results of this study should however be interpreted with caution, as the estimated Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) for the DAT group ranged from five to 22 and for VD group ranged from three to 21. This would suggest a great variability in cognitive ability in both groups and one might question whether individuals at the lower MMSE scores were able to give informed consent and fully participate or understand task instructions. In addition, no indication was given as to the possible aetiology of VD (e.g. haemorrhagic, ischemic or small vessel disease), highlighting the need for further methodologically sound research in the area of social cognition in VD.

There is however increasing evidence that individuals diagnosed with DAT may be impaired at key stages of emotion processing (Phillips, Scott, Henry, Mowat & Bell, 2010). Studies have shown individuals with DAT to be impaired in

recognising emotions from faces (Hargrave, Maddock, & Stone, 2002), voices (Roberts, Ingram, Lamar, & Green, 1996) or body movements (Koff, Zaitchik, Montepare, & Albert, 1999). However, these studies have tended to use small sample sizes and relied on the MMSE to classify DAT into mild, moderate and severe. The MMSE has been criticised for being insensitive to early stages of dementia, particularly in DAT (Mathuranath, Nestor, Berrios, Rakowicz, & Hodges, 2000). As a consequence, it is difficult to compare and generalise results from these studies, as it is possible that any impairments found may be due to an overall deterioration in cognitive skills rather than specific social cognition difficulties.

In addition, studies exploring emotion recognition in individuals with DAT have mainly relied on Ekman and Friesen's (1976) 60 Faces Test ([FEEST], Young et al., 2002]; Henry et al., 2008), a static display of black and white photographs of human faces displaying one of seven emotions: '*happy*', '*neutral*', '*revolted*', '*anxious*', '*sad*', '*angry*' or '*surprised*'. Results from these studies suggest impairments in identifying emotions across all stages of the disease progression (e.g. Phillips et al., 2010; Hargrave, Maddock, & Stone, 2002). The main difficulty in using static displays of emotion to assess emotion recognition abilities lies in the fact that the experimental conditions in which such tasks are assessed, are not replicable to real-life social exchanges (McDonald, Flanagan, Rollins & Kinch, 2003). Studies have tended to assess one modality of emotion recognition in isolation (e.g. visual or auditory emotion recognition), but this is not reflective of real-life scenarios of social interaction.

Henry and colleagues (2008) attempted to overcome these issues by using a

more ecologically valid measure of emotion recognition, the Emotion Recognition Test from the Awareness of Social Inference Test (TASIT-ERT, McDonald et al., 2003) in addition to a static emotion recognition task (i.e. FEEST). The TASIT-ERT comprises 28 video-vignettes in which a professional actor depicts one of seven possible emotions (e.g. happy, sad, neutral, surprised, angry, anxious or revolted) (McDonald et al., 2003). Henry et al. (2008) assessed three groups of participants, a group of young adults, a group of participants with DAT and a group of age-matched older healthy controls. Participants with DAT showed significant difficulties labelling static displays of emotions on the FEEST, for all emotions except '*disgust*', relative to both the younger and older control groups. A comparison between the three groups for the seven emotions displayed in the TASIT-ERT showed that older adults and participants with DAT's performance was significantly impaired in comparison to younger adults but no significant differences were found between the older controls and participants in the DAT group. Henry and colleagues (2008) concluded that it is possible that more traditional measures of affect recognition, i.e. FEEST, over-estimate the degree of impairment that participants with DAT experience in their day-to-day life. It should be highlighted that the critical task features responsible for the patterns of age and effects of DAT on the different emotion recognition tasks used in the Henry et al. (2008) study are difficult to define with precision, as there is no existing model relating to emotion processing in neurodegenerative conditions which explains the role of each of the possible variables involved in social cognition.

Several studies have suggested that individuals with DAT will often show preserved ToM, social comprehension, emotional reading and regulation skills as

long as their general cognitive ability is maintained (Goodkind, Gyurak, McCarthy, Miller, & Levenson, 2010; Lavenu et al., 1999; Rankin & Salazar, 2009; Zaitchik, Koff, Brownell, Winner, & Albert, 2004). ToM tasks, typically story narratives, place heavy demands on the cognitive resources of individuals with DAT (e.g. working memory). As such, some researchers have claimed that general cognitive decline may account for the deficits found in individuals with DAT in primary and second order belief ToM tasks (Fernandez-Duque, Baird & Black, 2009; Gregory et al., 2002; Shany-Ur et al., 2012; Zaitchik, Koff, Brownell, Winner, & Albert, 2006). Cuerva, Sabe, Kuzis, Tiberti, Dorrego and Starkstein (2001) examined ToM and pragmatic abilities in individuals with DAT. Over 65 per cent of individuals with DAT showed difficulties in the ToM task; in addition, participants who were impaired on the ToM task showed impaired performance in anterograde memory, verbal comprehension, abstract thinking and naming (Cuerva et al., 2001). Although it is not possible to infer causality from these findings, this study highlights the need to account for the effects of cognitive difficulties when assessing individual's ToM.

Considering that some of the most commonly reported factors affecting older people's mood relate to social isolation, loneliness, health and mental well-being (Bath & Deeg, 2005; House, Landi, & Umberston, 1988), it is crucial for researchers to further understand possible associations between interpersonal and behavioural factors and their predictors, such as social cognition skills (Phillips et al., 2010) in people with DAT. Behavioural changes in DAT pose a significant burden to carers and relatives (Cummings, 2005). The most commonly reported changes by carers include irritability, aggressiveness and apathy, all of which have been linked to increased caregiver distress (Serra et al., 2010). Collectively termed '*Behavioural*

and Psychological Symptoms of Dementia' or BPSD (IPA, 2002), these changes in behaviour can appear similar to those observed in individuals with identified social cognition difficulties, i.e. individuals with autism or TBI (Strong et al., 2009; Girardi, MacPherson & Abrahams, 2011). Consequently, researchers have begun to investigate associations between behaviour and social cognition in neurodegenerative conditions.

Behavioural changes, which can be commonly found following onset of a neurodegenerative conditions, may be explained by wider social cognition impairments (e.g. difficulties understanding and processing emotions) (Kipps, Mioshi, & Hodges, 2009). However, a broad range of methods for assessing each construct coupled with varied definitions and interpretations of each variable across studies makes it difficult to draw any conclusive results. Further methodologically sound investigations are needed in order to establish the association between social cognition and behaviour in neurodegenerative conditions, particularly in DAT patients (Elamin et al., 2012).

Finally, it is important to highlight the context within which changes to social cognition or behaviour in dementia may occur. Often, partners will assume the caring role as the patient with dementia gradually becomes more dependent (Garand et al., 2007). Inevitably, there may be changes in roles and in the relationship, which can affect a partner's mental and physical wellbeing and consequently the support they may be able to offer the patient with dementia. Gallagher-Thompson and colleagues (2001) explored the changes experienced by couples following a diagnosis of DAT and showed that partners of individuals with DAT were less

interactive and used simpler language when completing routine daily activities than partners of healthy-age matched controls. In addition, couples had a tendency to share less information compared to control couples. Furthermore, caregiving partners showed significantly higher levels of psychological distress in comparison to their matched counterparts (Gallagher-Thompson, Dal Canto, Jacob, & Thomson, 2001). It is often the case that partners are responsible for providing community-based care of older people (Lewis, 1998), including individuals with neurodegenerative conditions like dementia; this highlights the centrality of the spousal relationship in dementia care and the need to further understand positive and negative predictors of relationship quality in couples, particularly within the context of dementia. In addition, national policies, i.e. Scotland's National Dementia Strategy (2010) Dementia Strategy (DoH, 2009) and the Prime Minister's Dementia Challenge (2012) have highlighted the importance of supporting carers and families at all stages of the disease, in order to reduce future hospital and nursing home admissions and improve long-term care of the person with dementia. Considering the negative impact that behaviour change may have in caregiving and relationship quality, it is fundamental to understand the role of possible contributors and predictors of behaviour change in neurodegenerative conditions, for instance, the relationship between social cognition and behaviour change.

3.2. Aims of the Study

No study to date has examined the association between relationship quality, behaviour change and social cognition in individuals with DAT or mixed dementia. The present study aims to further assess the relationship between social cognition

and behaviour in neurodegenerative conditions as well as explore how both these factors are associated with relationship quality. The main hypotheses for this study are: 1) Participants with DAT or mixed dementia (participants with dementia; PWDs) will be impaired on a social cognition task in comparison to their partners; 2) There will be a significant negative correlation between performance on a social cognition task and behaviour ratings in PWDs, 3) There will be a significant positive correlation between social cognition in PWDs and partners' ratings of relationship quality; 4) There will be a significant negative correlation between behaviour in PWDs and partners' ratings of relationship quality; 5) There will be a significant positive correlation between social cognition in PWDs and partners' self-reported mood; 6) There will be a significant positive correlation between social cognition and general cognitive ability in PWDs.

3.3. Method

3.3.1 Participants

Twenty-seven participants with DAT (N=22) or mixed VD and DAT (N=5) and their partners were recruited. All couples were currently living together and had been married between 22 and 73 years (M = 51.81, SD = 10.83). Of the participants with dementia, 17 were female and 10 male; age ranged from 71 to 94 years (M: 78.9, SD: 4.83). Consultant Old Age Psychiatrists within the relevant health boards had made all dementia diagnoses, between one and 8 years previously (M: 3.37, SD: 1.67).

Inclusion criteria for PWDs were: i) a medical diagnosis of probable DAT or

mixed dementia according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINDS-ADRDA; McKhann et al., 1984) and DSM-V (APA, 2013) criteria, ii) mild to moderate DAT or mixed dementia with a score between 0.5 and 2 in the Clinical Dementia Rating[e] (CDR; Morris, 1997), iii) an absence of major depression or psychiatric disorder, as defined by DSM-V criteria (APA, 2013), iv) living with a partner who is willing to participate, v) English spoken fluently, vi) able to give informed consent to participate in the present research and vii) living at home with their partner. The exclusion criteria for PWDs were: i) a diagnosis of a learning disability, ii) autism/ Asperger's, iii) personality disorder, iv) significant visual or hearing impairments, v) a TBI with unconsciousness lasting over 5 minutes and vi) major stroke with significant cognitive impairments.

The comparison group in this study was individuals who had been in a long-term relationship, marriage or civil partnership, for at least five years with the participant with DAT or mixed dementia. Partners (17 male/ 10 female) were between the ages of 65 and 96 years (M: 78, SD: 6.22) (Table 3.1). The inclusion criteria for partners were: i) Absence of major depression or psychiatric disorder, as defined by DSM-V criteria (APA, 2013), ii) have lived with the PWD in the past for at least 5 years or more and currently living with them, iii) English spoken fluently, iv) able to give informed consent to participate in the present research. The exclusion criteria for partners of individuals with dementia was: i) A diagnosis of a learning disability, ii) autism/ Asperger's, iii) personality disorder, iv) significant visual or hearing impairments, v) diagnosis of dementia or any other cognitive impairment, vi)

[e] As per SDCRN volunteer database score in August 2012.

TBI with unconsciousness lasting over 5 minutes or vii) stroke with significant cognitive impairments.

All participants (PWDs and partner groups) were recruited through the Scottish Dementia Clinical Research Network (SDCRN) across two health boards in Scotland. The study received ethical approval from the Scotland Research Ethics Service ( ) in May 2012, was conducted in accordance with the Declaration of Helsinki and all volunteers gave their informed consent to participate.

Prospective power analyses were conducted to estimate the sample size required to ensure the methodological integrity of the present study. In terms of significance criterion, an alpha (α) level of .05 is generally recommended in behavioural sciences research in order to reduce the risk of committing a Type I error, whereby the null hypothesis is mistakenly rejected (Cohen, 1992). Cohen's power primer method (1992) suggests that in order to have .8 power to detect medium effect sizes at an alpha level of .05 when carrying out a multiple regression/correlation analysis with two independent variables, a sample size of 67 is required. Although the study aimed to recruit 60-70 participants; 54 participants were recruited in total.

3.3.2 Measures

Both groups were asked to complete a battery of neuropsychological and mood assessment measures. The battery included a cognitive screen, the ACE-R (Mioshi et al., 2006), a measure of social cognition, the Awareness Social Inference Test (TASIT, McDonald, et al., 2003), a premorbid measure of intelligence (WTAR)

and a screen for emotional distress. Partners were asked to additionally complete a measure of relationship quality and a screen for behavioural disturbance.

3.3.2.1 Cognitive Screening: The Addenbrooke Cognitive Examination Revised (ACE-R, Mioshi et al., 2006).

This is a brief, sensitive and specific cognitive screening test which incorporates five subdomain scores: orientation/attention, memory, verbal fluency, language and visuo-spatial abilities. Mioshi et al. (2006) found sound psychometric properties for this measure, with good reliability (α= 0.8) and validity, showing significant correlations with the CDR (r=.321, p<.01). Standardised norms are available for individuals aged 46 to 86 years. Four participants with DAT and two partners were excluded from the analysis as they were aged over 86 years.[f]

3.3.2.2 Premorbid Assessment: The Wechsler Test of Adult Reading (WTAR, Psychological Corporation, 2001).

This is a brief assessment of estimated premorbid ability that requires participants to read 50 irregularly spelled words. This assessment has standardised norms for individuals aged 16-89 years. Our sample included two patients and one partner over the age of 89, who were excluded from group comparisons. According to the test manual, the WTAR shows excellent psychometric properties with internal consistency for the various age groups with coefficients raging from.87 to .95 for the UK sample (Psychological Corporation, 2001). Performance also appears to be stable over time. The WTAR shows high correlations with other measures of reading

[f] The ACE-R has now been replaced by the ACE-III (Mioshi et al., 2012) due to copyright issues. No consensus had been reached regarding the copy rights of the ACE-R at the time of the study's commencement.

(e.g. AMNART, r= .90, p<.01; WRATR, r= .73, p<.01, WTAR, 2001) as well as with other measures of general intelligence and memory (e.g. WAIS-III VIQ, r= .74, p<.01; FSIQ, r= .73, p<.01) (WTAR, 2001).

3.3.2.3 Social Cognition Assessment: The Adult Social Inference Test (TASIT, McDonald, Flanagan, Rollins & Kinch, 2003).

The TASIT is an audio-visual tool designed for the clinical assessment of social perception with alternate forms for re-testing. Part I of the TASIT, the Emotion Recognition Test (TASIT-ERT), shows 28 short video-vignettes (20 to 40 seconds each) of individuals depicting one of seven emotions: '*happy', 'surprised', 'neutral', 'sad', 'angry', 'anxious'* or *'revolted'*. Part II of the TASIT, the Social Inference-Minimal (TASIT-SIM) test, shows 15 short video-vignettes (20 to 40 second each) of everyday conversational exchanges. This test examines a person's understanding of conversational meanings determined by paralinguistic cues such as facial expression, tone of voice or gestures. The video vignettes in this test use neutral scripts, which are enacted by professional actors and can represent either '*sincere*' or '*sarcastic*' (simple and complex) social exchanges. An individual's ability to understand these social exchanges is then assessed using four questions regarding the actor's beliefs (i.e. what they know), meaning (i.e. what they mean by what is said), intentions (i.e. what they intend to do) and feelings (i.e. what they feel) (McDonald et al., 2003).

Part III of the TASIT, the Social Inference-Enriched test (TASIT-SIE), shows 16 short video-vignettes (20-40 seconds each) of everyday conversational exchanges. Each vignette contains a literally untrue comment enacted in one of two

ways: as sarcasm meant to amplify the truth or as a lie meant to conceal or minimise the truth. This test distinguishes between visual and text cues to determine the meaning of paralinguistic features and assesses an individual's understanding of the situation using the same four questions as in Part II: beliefs, meaning, intentions and feelings (McDonald et al., 2003). As per TASIT manual (Rollins, Flanagan, & McDonald, 2002), composite scores can be created in all three parts of the TASIT by adding the relevant sub-scores. The composite scores in each part are: Part I include '*positive*',(i.e. the sum of '*surprise*', '*happy'* and '*neutral'* scores) '*negative*'(i.e. the sum of '*revolted'*, '*sad*', '*angry'* and '*anxious*' scores) and ' *Total ERT*' (i.e. the sum of both *'positive'* and *'negative'* total scores), part II include, *'sincere'*, *simple sarcasm'*, ' *complex sarcasm'* and '*Total SIM'* (i.e. the sum of *'sincere', simple'* and *'complex sarcasm')* and part III include '*textual'*, '*visual'* and '*Total SIE'* (the sum of '*textual*' and '*visual'* scores) composite scores.

The psychometric properties of the TASIT were assessed by McDonald et al. (2006) with individuals with severe TBIs. Test re-test reliability ranged from 0.74-0.88; while alternate forms of reliability ranged from 0.62 to 0.83. McDonald et al. (2006) showed significant associations with other measures of social cognition (e.g. FEEST, r= .69, p<.01 [TASIT-ERT], r= .50, p<.01 [TASIT-SIM], r= .37, p<.01 [TASIT-SIE]; First/second order ToM r= .68, p<.05 [TASIT-SIM]).

3.3.2.4 Behaviour Measure: Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D, Cummings, 1994; Kaufer et al., 1998).

The NPI-D assesses psychopathology in dementia by evaluating twelve common neuropsychiatric disturbances in dementia, their severity and their frequency are measured using a likert scale from '*never present'* to '*behaviour*

present more than once a day': '*delusions*', '*hallucinations*', '*agitation'*, '*dysphoria'*, '*anxiety'*, '*apathy'*, '*irritability'*, '*euphoria'*, '*disinhibition'*, '*aberrant motor behaviour*', '*night-time behaviour disturbances*' and '*appetite and eating abnormalities*'. The NPI-D also assesses the amount of caregiver distress engendered by each of the neuropsychiatric disorders. Cummings (1997) established content validity (subjectively), concurrent validity (e.g. Hamilton Depression scale [HDS, Hamilton, 1960], all correlations $p< .05$), inter-rater reliability (93.6 to 100%), and test re-test reliability ($r =. 79$, $p<.01$ [frequency], $r=.86$, $p<.01$ [severity]) of the NPI-D.

3.3.2.5 Relationship Measure: The Birmingham Relationship Continuity Measure (BRCM, Riley et al., 2013).

This scale has been validated to measure relationship continuity when caring for a partner with dementia. The BRCM is a 26-item instrument measuring caregivers' perceived continuity of spousal relationship, where one individual in the couple cares for the other, due to a diagnosis of dementia. The BRCM contains six domains: i) changes in relationship; ii) changes to the person; iii) changes in feelings; iv) sense of loss; v) sharing and togetherness and vi) expressions of affection and attachment. Each item in the BRCM is scored using a Likert scale from 1 '*disagree a lot'* to 5 '*agree a lot'*. The psychometric properties of this scale were assessed by Riley et al. (2013) and showed good internal consistency (Cronbach's $\alpha= .94$), good test-retest reliability ($\alpha= .96$) and good concurrent validity (e.g. Closeness and conflict scale, $r=. .43$, $p<.05$; (Marwit-Meuser Caregiver Grief Inventory [MMCG-I; Marwit & Meuser, 2002] $r= .54$, $p<.01$). Scores for the relationship continuity scale, as rated by partners on this study were normally distributed (M=76.04, SD= 22.39).

3.3.2.6 Mood Assessment: The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983).

The HADS consists of two seven-item subscales, one measuring anxiety and the other subscale measuring depression. These are scored separately and give an indication of an individual's symptomatology for each scale. Bjelland and colleagues (2002) reviewed the psychometric properties of the HADS in assessing symptom severity of anxiety and depression in both somatic, psychiatric, primary care patients and the general population. Their results showed good correlations between both scales, varying from .40 to .74 (*M*= .56). Cronbach's α for HADS-A varied from .68 to .93 (M= .83) and for HADS-D from .67 to .90 (*M*= .82). The HADS has been recommended as an outcome measure with older people by the Centre for Outcomes, Research and Effectiveness (CORE) and the British Psychological Society (BPS) in terms of practicality, feasibility, UK relevance, psychometric properties and contents (CORE & BPS, 2004). Although routinely used to assess anxiety and depression symptomatology in DAT or VD in clinical practice, only a few studies have used the HADS as a measure of mood symptomatology in neurodegenerative conditions such as DAT (e.g. Wands et al., 1990).

3.3.3 Procedure

The SDCRN provided names and contact details of 264 participants (132 couples) within their volunteer panel that met the initial inclusion and exclusion criteria. All 132 couples were initially sent information on the present research by post, followed by a telephone call from the primary researcher (BP) to offer them the opportunity to participate. Twenty-seven couples (10.23%) met with the Chief Investigator and agreed to participate in the present study.

During the initial meeting, all participants were provided with a Participant Information Sheet (PIS) and were encouraged to ask questions about the study. Participants who expressed an interest in taking part in the study were then asked to complete a consent form, by which they agreed to meet the primary researcher to carry out some assessments for the study. Their own general practitioners were informed by post that a participant in the volunteer pool was taking part in the research, according to SDCRN guidelines.

The recruitment process offered potential participants a number of specific instances to decline to taking part in the study before the assessment was started: (i) When they were contacted by phone by the primary researcher to confirm their initial interest to take part, (ii) When they attended a meeting with the primary researcher and, (iii) When they met the primary researcher to begin the assessment.

During the initial assessment session, demographic information was collected from the PWD and their partner. All participants were tested individually at their home. Counterbalancing of test materials was carried out and testing was spread across two sessions in order to account for the impact of fatigue on performance. During the first session, both groups completed the ACE-R, WTAR and the self-version of the HADS. In addition, partners completed proxy ratings of behaviour and relationship quality at the time of the first assessment session using the NPI-D and BRCM. Both groups completed the TASIT during the second appointment. The TASIT was reproduced in the main using participants' own home equipment, i.e. DVD players, on a television set (screen size at least 30 inches)[g]. Where this was not available, a personal 13-inch laptop was used at eye level for participants to watch

[g] Television screens varied from 30 inches to approximately 45 inches.

the video-vignettes. Each video-vignette was only shown once. Each appointment lasted a maximum of 90 minutes.

3.3.4 Data Analysis

Non-parametric testing (Mann–Whitney U) was used to compare groups on demographic information (age, WTAR) and total ACE-R scores. Emotion recognition scores for Part I of TASIT (TASIR-ERT), part II (Test of Social Inference-Minimal, TASIT-SIM) and part III (Test of Social Inference-Enriched, TASIT-SIE) were not normally distributed for the partner group and thus comparisons across groups were analysed using Mann-Whitney U tests. Non parametric measures of association (Spearman's Rho) were used to test associations between social cognition scores, relationship quality, partners' mood, cognitive functioning skills and proxy ratings of behaviour. In order to account for Type I error in multiple correlations, the critical α level was reduced to .01 as recommended by Field (2009). Not all PWDs were able to complete every part of the TASIT, part I (N= 26), part II (N= 23) and part III (N=22).

3.4. Results

3.4.1 Exploratory Data Analysis

The study contacted 132 couples, of which 27 agreed to participate (20 per cent).

Data were initially examined for normality of the distribution. Tests of skewness and

kurtosis[h] were performed for the variables: age and total scores on the WTAR, ACE-R, BRCM, NPI-D, HADS-A, HADS-D and TASIT (ERT, SIM and SIE). A ceiling effect was identified for partners' ACE-R total scores. Partners' data were non-normally distributed for total scores on the ACE-R (D [27] = .02, p < .05), HADS-A (D [27] = .0, p < .05), NPI-D (D [27] = .0, p < .05), TASIT-ERT (D [27] = .02, p < .05), and TASIT-SIE (D [27] = .0, p < .05). The PWD group data was found non-normally distributed for TASIT-SIE (D [22] = .04, p < .05), and HADS-D (D [27] = .02, p < .05). Data for the relevant variables was transformed using a Log10 transformation as recommended by Field (2009) in an attempt to correct for distributional difficulties. However, even after transformation, tests of normality still showed data for these variables as non-normally distributed. Levene´s test was significant (p < .01) for the ACE-R, F (1,52)=16.70, P< .01, TASIT-SIM, F (1,551) = 14.52, P< .01 and TASIT-SIE, F (1,48)=6.37, P< .01 indicating that variances were significantly different and the homogeneity of variance assumption was not tenable for these scores.

The study used missing value analysis as recommended by Field (2009) to manage missing data in our database, i.e. a numeric code was used to represent the missing values in the data. Only five participants were unable to complete TASIT-SIE, the most complex of the three TASIT tasks.

3.4.2 Descriptive Statistics

3.4.2.1 Demographic data

[h] Scores were then converted into z-scores following recommendations by Field (2009), where a z score more than +/- 1.96 for large samples or +/- 2.58 for smaller samples signifies a non-normally distributed sample.

Descriptive statistics for age, standard WTAR score and ACE-R total score showed the partners and PWDs groups were matched for age and estimated premorbid cognitive ability (Table 3.1). Significant differences, U (48) = 13, Z = 6.1, p = .0005, were found between PWDs and their partners' general cognitive ability as measured by the ACE-R (Table 3.1).

Table 3.1. *Demographic Data*

	DAT/Mixed dementia			Partners			U-test	*z*	Sig.
	N	Median	Range	N	Median	Range			
Age	27	77.5	71-94	27	78	65-96	456.5	1.59	*n.s*
WTAR std.	26	110	86-123	25	112	92-125	275.5	1.54	*n.s*
ACE-R	23	70.50	50-83	25	94	81-100	13	6.10	p<.001

Note. N: number of participants, WTAR std: Wechsler Test of Adult Reading Standard Score, ACE-R: Addenbrooke's Cognitive Examination Revised, U-test: Mann-Whitney U statistic, z: standardised test statistic, Sign: significance level, *n.s:* not significant.

3.4.2.2 Mood symptomatology

Mann-Whitney U tests assessed differences in anxiety and depression scores on the HADS. No significant differences were found in anxiety or depression scores between partners and PWDs.

Table 3.2. *Anxiety and Depression Scores as Measured by the HADS*

	DAT/Mixed dementia			Partners			U-test	*z*	Sign.
	N	Median	Range	N	Median	Range			
Anxiety	27	9	3-14	27	4	1-12	298.5	-1.15	*n.s*
Depression	27	4	0-8	27	4	0-11	354.5	-.18	*n.s*

Note. N: number of participants, U-test: Mann-Whitney U statistic, z: standardised test statistic, Sign: significance level, *n.s:* not significant.

3.4.2.3 Behaviour data

The NPI-D total scores were examined for PWDs. The most frequently reported behaviour changes in PWDs by partners on the NPI-D were apathy (N=20), anxiety (N=14) and irritability (N=11) followed by agitation (N=10) and appetite changes (N=10). Apathy appeared to be the most distressing for partners, followed by irritability, anxiety and depression.

3.4.3 Main Results

3.4.3.1 Hypothesis 1: Social cognition performance in PWDs will be impaired in comparison to the partners' group

To compare performance between partners and PWDs' groups on TASIT (ERT, SIM and SIE) scores, non-parametric Mann Whitney-U tests were performed.

3.4.3.1.1 ***Comparison of TASIT-ERT scores between partners and PWD.*** Mann Whitney U tests revealed significant differences between PWDs and partners for all emotions, i.e. '*surprised*', '*neutral*', '*sad*', '*anxious*', '*angry*' and '*revolted*', with the exception of '*happy*'. Median and ranges are shown in Table 3.3 and suggest partners performed significantly better at recognising all seven emotions than PWDs. Composite scores were created following a standard accepted approach contained in the TASIT manual (Rollins, Flanagan, & Skye, 2002) for positive emotions by adding '*happy*', '*surprised*' and '*neutral*' total scores for each group, and negative emotions, by adding '*angry*', '*anxious*', '*sad*' and '*revolted*' total

scores. Mann Whitney U tests revealed significant differences between groups for positive, negative and total TASIT-ERT scores between PWDs and partners (Table 3.3), where partners obtained higher scores.

3.4.3.1.2 ***Comparison of TASIT-SIM scores between partners and PWD groups***. The PWD's group ability to understand what the video vignettes actors' beliefs, meaning, intentions and feelings, were significantly poorer compared to the partners (Table 3.4). Grouping '*sincere*', '*simple sarcastic*' and '*complex sarcastic*' social exchanges as per the standard accepted approach contained in the TASIT manual (Rollins, Flanagan, & Skye, 2002) created three composite scores that afforded the opportunity to examine whether individuals in each condition (partner v. PWDs) showed differences in their understanding of different types of social exchange. The PWD's group ability to understand and distinguish between '*sincere*' and '*simple sarcastic'* and '*complex sarcastic*' social exchanges was significantly poorer compared to partners' ability. Mann Whitney U tests also revealed significant differences between PWDs and partners' TASIT-SIM total scores (Table 3.4). From examination of the median and ranges, partners showed the highest scores in comparison to PWDs group.

3.4.3.1.3 ***Comparison of TASIT-SIE scores between partners and PWD groups***. Mann Whitney U tests for TASIT-SIE scores revealed significant differences between partners and PWDs groups. The ability to understand what the video vignettes actors' beliefs, meaning, intentions and feelings, were significantly poorer in PWDs compared to partners'. Significant differences were found between PWDs and partners groups in all elements of the TASIT-SIE despite the main

paralinguistic cue used (Table 3.5).

Table 3.3 *Performance on the TASIT Emotion Recognition Test (TASIT-ERT).*

	DAT/Mixed dementia			Partners			U-test	*z*	*r*	Sign.
	N	Median	Range	N	Median	Range				
Happy	26	3	2-4	27	4	2-4	269	1.61	-0.22	*n.s*
Surprised	26	1.5	0-4	27	4	2-4	50	5.60	-0.77	.0005
Neutral	26	1	0-4	27	3	2-4	65	5.22	-0.72	.0005
Sad	26	2	0-4	27	4	2-4	142.5	3.92	-0.54	.0005
Angry	26	2	0-4	27	4	3-4	114	4.46	-0.61	.0005
Anxious	26	3	0-4	27	4	1-4	132	4.20	-0.58	.0005
Revolted	26	1	0-4	27	4	2-4	96	4.69	-0.64	.0005
Negative Emotions	26	6.5	3-12	27	11	8-12	36	5.64	-0.77	.0005
Positive Emotions	26	9	3-14	27	15	9-16	29	5.77	-0.79	.0005
ERT Total	26	15	7-26	27	24	20-28	20	5.91	-0.81	.0005

Note. N: number of participants, U-test: Mann-Whitney U statistic, *r*: effect size, z: standardised test statistic, Sign: significance level, *n.s:* not significant, ERT: Emotion recognition test.

Table 3.4. *Performance on TASIT Test of Social Inference-Minimal (TASIT-SIM).*

	DAT/Mixed dementia			Partners			U-test	*z*	*r*	Sign.
	N	Median	Range	N	Median	Range				
Do	23	9	3-14	27	13	9-15	86	4.41	-0.62	.0005
Say	23	9	3-13	27	12	8-15	87	4.39	-0.63	.0005
Think	23	9	3-13	27	12	8-15	98.5	4.16	-0.59	.0005
Feel	23	9	2-13	27	13	7-15	75	4.62	-0.66	.0005
Sincere	23	14	9-20	27	18	14-20	124	3.66	-0.52	.0005
Simple Sarcasm	23	10	2-20	27	16	8-20	123	3.66	-0.52	.0005
Paradoxical Sarcasm	23	11	0-15	27	17	7-20	56.5	4.97	-0.71	.0005
SIM Total	23	38	11-47	27	49	38-58	29	5.49	-0.78	.0005

Note. N: number of participants, U-test: Mann-Whitney U statistic, *r*: effect size, z: standardised test statistic, Sign: significance level, SIM Total: Test of social inference minimal scores.

Table 3.5. *Performance on TASIT Test of Social Inference-Enriched (TASIT-SIE).*

	DAT/Mixed dementia			Partners			U-test	*z*	*r*	Sign.
	N	Median	Range	N	Median	Range				
Do	22	8	4-13	27	14	10-16	21.5	5.58	-0.80	.0005
Say	22	8	6-14	27	14	11-16	24.5	5.53	-0.79	.0005
Think	22	8.5	4-14	27	14	10-16	29	5.42	-0.77	.0005
Feel	22	8	5-12	27	13	10-16	22	5.56	-0.79	.0005
Visual Sarcasm	22	10	2-20	27	16	8-20	31.5	5.38	-0.77	.0005
Visual Lie	22	10	4-14	27	14	10-16	44	5.12	-0.73	.0005
Visual Total	22	17.5	10-27	27	29	22-31	12	5.76	-0.82	.0005
Text Sarcasm	22	7	1-12	27	12	8-15	35	5.30	-0.76	.0005
Text Lie	22	8	5-12	27	14	10-16	39	5.22	-0.74	.0005
Text Total	22	16.5	9-27	27	28	12-31	29	5.40	-0.77	.0005

Note. N: number of participants, U-test: Mann-Whitney U statistic, *r*: effect size, z: standardised test statistic, Sign: significance level.

3.4.3.2 Hypothesis 2: There will be a significant negative correlation between performance on a social cognition task and behaviour change ratings in PWDs

Spearman correlations were conducted between social cognition scores, TASIT ERT, SIM and SIE, and NPI-D total and each behaviour ratings. There were no significant correlations ($p < .01$) between social cognition scores (TASIT-ERT, SIM and SIE) and NPI-D total and specific behaviour ratings by partners (Table 3.6, 3.7. and 3.8.).

3.4.3.3 Hypothesis 3: There will be a significant positive correlation between social cognition in PWDs and partner's ratings of relationship quality

Spearman correlations revealed no significant correlations between partners' BRCM ratings and PWDs social cognition as measured by the TASIT (ERT, SIM and SIE) (Table 3.9).

3.4.3.4 Hypothesis 4: There will be a significant negative correlation between behaviour changes in PWDs and partners' ratings of relationship quality

The association between behaviour changes in PWDs, as measured by the NPI-D, and relationship quality scores, BRCM, was tested using Spearman correlations. No cut-off scores exist for the BRCM at present, thus it is not possible to categorise couples' relationships. Significant negative correlations were found between total score on the BRCM and '*apathy*' (*rho*= -.64, $p < .001$). With regards

to frequency of behaviours, significant negative correlations were found between scores on the BRCM and frequency of '*disinhibition*' (*rho*= -.53, $p < .001$), suggesting that the more frequently disinhibited behaviour appears, the poorer relationship quality as rated by partners. The NPI-D also gives scores for severity and how distressing raters find each of the behaviours displayed. With regards to severity, the more severe the '*apathy*' (*rho*= -.67, $p < .001$) and '*disinhibition*' behaviours (*rho*= -.53, $p < .001$), the poorer the relationship quality was judged by partners.

With regard to distress, significant negative correlations were found between the total scores on the BRCM and how distressing they found the following behaviours: '*agitation*' (*rho*= -.51 $p<.001$), '*apathy*' (*rho*= -.63, $p < .001$) and '*disinhibition*' (*rho*= -.54, $p < .001$).

Finally, significant negative correlations were found between the BRCM total scores and the NPI-D total scores (*rho*= -.70, $p < .001$), and NPI-D total distress scores (*rho*= -.71, $p < .001$), suggesting that greater presence of behaviours and the more disrupting the behaviours were rated overall, the poorer the relationship quality as rated by the partners (Table 3.10).

3.4.3.5 Hypothesis 5: There will be a significant positive correlation between social cognition in PWDs and partners' mood

There were no significant correlations between partners' anxiety and depression symptomatology as measured by the HADS and PWDs social cognition as measured by the TASIT (ERT, SIM and SIE) (Table 3.11).

Table 3.6. *Spearman Correlations between TASIT (ERT) and NPI Scores*.

		NPI Behaviour Changes													
		A	B	C	D	E	F	G	H	I	J	K	L	NPI Total	NPI Distress
ERT Positive	*Rho*	-0.15	-0.28	-0.21	-0.10	-0.28	-0.28	0.09	-0.27	-0.20	-0.02	-0.24	-0.28	-0.28	-0.25
	Sig. (2-tailed)	0.46	0.18	0.31	0.61	0.17	0.18	0.67	0.19	0.34	0.91	0.24	0.17	0.17	0.23
ERT Negative	*Rho*	-0.18	0.01	-0.17	-0.04	-0.35	-0.24	0.28	-0.32	0.21	-0.06	-0.24	0.06	-0.03	-0.14
	Sig. (2-tailed)	0.38	0.97	0.41	0.83	0.06	0.25	0.17	0.11	0.31	0.78	0.24	0.77	0.90	0.50
ERT Total	*Rho*	-0.15	-0.16	-0.15	-0.07	-0.20	-0.29	0.22	-0.35	0.09	0.01	-0.26	-0.09	-0.11	-0.16
	Sig. (2-tailed)	0.47	0.44	0.45	0.73	0.07	0.16	0.28	0.08	0.67	0.96	0.20	0.66	0.60	0.44

Note. NPI: Neuropsychiatric Inventory, A: Delusions, B: Hallucinations, C: Agitation, D: Depression, E: Anxiety, F: Elation, G: Apathy, H: Disinhibition, I: Irritability, J: Aberrant Motor Behaviour, K: Night Time Behaviour, L: Appetite Changes, ERT: Emotion Recognition Test, Rho: Spearman's Correlation Coefficient, Sig.: Significance level.

Table 3.7. *Spearman Correlations between TASIT (SIM) and NPI Scores*.

		NPI Behaviour Changes													
		A	B	C	D	E	F	G	H	I	J	K	L	NPI Total	NPI Distress
SIM Sincere	*Rho*	-0.01	0.25	-0.29	-0.02	0.13	0.14	-0.32	-0.15	-0.29	-0.20	-0.32	-0.25	-0.19	-0.20
	Sig. (2-tailed)	0.96	0.26	0.19	0.93	0.57	0.52	0.14	0.10	0.18	0.36	0.14	0.26	0.38	0.37
SIM Simple Sarcasm	*Rho*	-0.34	-0.02	-0.17	0.28	0.29	-0.14	-0.13	-0.18	0.15	0.01	-0.25	0.20	-0.02	0.07
	Sig. (2-tailed)	0.11	0.93	0.44	0.20	0.18	0.53	0.56	0.42	0.49	0.97	0.26	0.36	0.92	0.76
SIM Complex Sarcasm	*Rho*	-0.20	-0.22	-0.30	-0.01	-0.11	-0.23	-0.20	-0.36	-0.23	-0.18	-0.27	-0.39	-0.23	-0.34
	Sig. (2-tailed)	0.37	0.06	0.17	0.98	0.61	0.30	0.35	0.09	0.29	0.41	0.21	0.07	0.30	0.11
SIM Total	*Rho*	-0.16	-0.28	-0.27	0.10	0.15	-0.08	-0.25	-0.35	-0.21	-0.07	-0.36	-0.16	-0.12	-0.18
	Sig. (2-tailed)	0.48	0.19	0.21	0.66	0.51	0.72	0.26	0.10	0.35	0.75	0.09	0.47	0.60	0.42

Note. NPI: Neuropsychiatric Inventory, A: Delusions, B: Hallucinations, C: Agitation, D: Depression, E: Anxiety, F: Elation, G: Apathy, H: Disinhibition, I: Irritability, J: Aberrant Motor Behaviour, K: Night Time Behaviour, L: Appetite Changes, SIM: Social Inference-Minimcal Test, Rho: Spearman's Correlation Coefficient, Sig.: Significance level.

Table 3.8. *Spearman Correlations between TASIT (SIE) and NPI Scores*.

		NPI Behaviour Changes													
		A	B	C	D	E	F	G	H	I	J	K	L	NPI Total	NPI Distress
SIE Total	*Rho*	0.21	-0.27	-0.27	0.17	0.01	-0.13	-0.19	-0.24	-0.27	0.02	-0.38	-0.42	-0.10	-0.22
	Sig. (2-tailed)	0.34	0.22	0.23	0.46	0.95	0.56	0.39	0.29	0.23	0.92	0.08	0.05	0.65	0.32
SIE Visual Cue	*Rho*	0.38	0.00	-0.13	0.29	0.34	-0.15	0.01	-0.09	-0.07	0.19	-0.33	-0.18	0.10	0.03
	Sig. (2-tailed)	0.09	1.00	0.57	0.19	0.12	0.51	0.97	0.70	0.75	0.41	0.14	0.43	0.66	0.88
SIE Textual Cue	*Rho*	0.08	-0.26	-0.20	0.10	-0.15	0.06	-0.32	-0.26	-0.31	-0.06	-0.28	-0.13	-0.10	-0.23
	Sig. (2-tailed)	0.74	0.24	0.37	0.67	0.50	0.80	0.15	0.24	0.16	0.80	0.20	0.15	0.65	0.30

Note. NPI: Neuropsychiatric Inventory, A: Delusions, B: Hallucinations, C: Agitation, D: Depression, E: Anxiety, F: Elation, G: Apathy, H: Disinhibition, I: Irritability, J: Aberrant Motor Behaviour, K: Night Time Behaviour, L: Appetite Changes, SIE:Social Inference-Enriched Test, Rho: Spearman's Correlation Coefficient, Sig.: Significance level.

Table 3.9. *Spearman Correlations between the BRCM and TASIT Total Scores*.

		ERT Positive	ERT Negative	ERT Total	SIM Sincere	SIM Simple Sarcasm	SIM Complex Sarcasm	SIM Total	SIE Visual Cue	SIE Text Cue	SIE Total
BRCM	*Rho*	0.14	0.04	0.07	0.19	0.24	0.19	0.22	0.02	0.29	0.26
	Sig. (2-tailed)	0.51	0.84	0.72	0.39	0.28	0.38	0.32	0.95	0.19	0.25

Note. BRCM: Birmingham Relationship Continuity Measure, ERT: Emotion Recognition Test, SIM: Social Inference Minimal, SIE: Social Inference Enriched, Rho: Spearman's Correlation Coefficient, Sig.: Significance level.

Table 3.10. *Spearman Correlations between BRCM and NPI (presence, severity, frequency and distress).*

		A	B	C	D	E	F	G	H	I	J	K	L
							PRESENCE						
BRCM	*Rho*	-0.20	0.03	-0.34	-0.21	-0.02	-0.35	-.64**	-0.48	-.039	-0.36	-0.31	-0.36
	Sig. (2-tailed)	0.06	0.87	0.08	0.30	0.91	0.08	0	0.05	0.05	0.07	0.12	0.07
							FREQUENCY						
	Rho	-0.39	-0.1	-0.4	-0.2	0.0	-0.43	-0.11	-.53**	-0.12	-0.43	-0.33	-0.28
	Sig. (2-tailed)	0.05	0.69	0.07	0.31	0.99	0.03	0.12	0.01	0.23	0.03	0.09	0.16
							SEVERITY						
	Rho	-0.40	-0.06	-0.33	-0.38	0.03	-0.34	-.67**	-.53**	-0.04	-0.20	-0.32	-0.32
	Sig. (2-tailed)	0.04	0.77	0.10	0.05	0.89	0.05	0.00	0.01	0.06	0.12	0.11	0.11
							DISTRESS						
	Rho	-0.41	-0.19	-.51**	-0.38	-0.10	-0.12	-.63**	-.54**	-.024	-0.35	-0.33	-0.42
	Sig. (2-tailed)	0.05	0.34	0.01	0.05	0.61	0.33	0.00	0.00	0.13	0.07	0.09	0.05

Note. NPI: Neuropsychiatric Inventory, A: Delusions, B: Hallucinations, C: Agitation, D: Depression, E: Anxiety, F: Elation, G: Apathy, H: Disinhibition, I: Irritability, J: Aberrant Motor Behaviour, K: Night Time Behaviour, L: Appetite Changes, BRCM: Birmingham Relationship Continuity Measure, Rho: Spearman's Correlation Coefficient, Sig.: Significance level. [m]

[m] In order to account for Type I error in multiple correlations, the critical α level was reduced to .01 as recommended by Field (2009).

Table 3.11. *Spearman Correlations between Partner's HADS Scores and Clinical Sample TASIT Total Scores*

		ERT Positive	ERT Negative	ERT Total	SIM Sincere	SIM Sarcasm	SIM Complex Sarcasm	SIM Total	SIE Total	SIE Visual Cue	SIE Text Cue
HADS Anxiety	*Rho*	0.1	0.288	0.27	-0.159	-0.026	0.069	-0.083	-0.158	-0.052	-0.185
	Sig. (2-tailed)	0.629	0.154	0.182	0.469	0.908	0.755	0.708	0.481	0.819	0.41
HADS Depression	*Rho*	-0.145	0.219	0.117	-0.352	-0.106	-0.006	-0.133	0.013	0.213	-0.157
	Sig. (2-tailed)	0.48	0.282	0.568	0.099	0.629	0.98	0.547	0.952	0.341	0.485

Note. HADS: Hospital Anxiety and Depression Scale, ERT: Emotion Recognition Test, SIM: Social Inference Minimal, SIE: Social Inference Enriched, Rho: Spearman's Correlation Coefficient, Sig.: Significance level.

3.4.3.6 Hypothesis 6: There will be a significant positive correlation between social cognition and general cognitive ability in PWDs

Spearman correlations between ACE-R total scores and TASIT (ERT, SIM and SIE sub-scores) were performed. Spearman correlations between TASIT ERT scores and ACE-R cognitive domains revealed that better attention, fluency and language scores in PWDs were related to better ability to recognise emotions (Table 3. 12).

Table 3.12. *Spearman Correlations between the ACE-R and TASIT (ERT) Scores*.

		ACE-R Subtests					
		Attention	Memory	Fluency	Language	Visuo-Spatial	ACE-R Total
ERT Positive	*Rho*	.50**	0.33	0.50	.50**	0.48	.60**
	Sig. (2-tailed)	.009	0.09	0.05	0.002	0.02	0.001
ERT Negative	*Rho*	0.39	0.46	0.39	0.44	0.35	.53**
	Sig. (2-tailed)	0.04	0.06	0.04	0.02	0.07	0.004
ERT Total	*Rho*	0.48	0.45	0.54	.55**	0.46	.57**
	Sig. (2-tailed)	0.03	0.02	0.02	0.002	0.02	0.000

Note. n.s: not significant; ACE-R: Addenbrooke's Cognitive Examination Revised; ERT: Emotion Recognition Test from TASIT, Rho: Spearman's Correlation Coefficient, Sig.: Significance level. ** Significant at p <.001.

Correlations between TASIT-SIM and general cognitive ability as measured by the ACE-R showed significant associations were present only for '*complex sarcasm*' scores, meaning that better fluency (*rho*= .56, *p*< .001), language (*rho*= .59, *p*< .001), visuo-spatial (*rho*= .58, *p*< .001) and total ACE-R scores (*rho*= .60, *p*< .001), were associated with better understanding of complex sarcastic situations as measures in the TASIT-SIM (Table 3.13). No significant correlations were found between TASIT-SIE and general cognitive ability as measured by the ACE-R (Table

3.14).

Table 3.13. *Spearman Correlations between ACE-R and TASIT (SIM) Scores*.

		ACE-R Subtests					
		Attention	Memory	Fluency	Language	Visuo-spatial	ACE-R Total
SIM Sincere	*Rho*	-0.32	-0.14	0.16	0.18	0.23	0.04
	Sig. (2-tailed)	0.14	0.54	0.44	0.39	0.28	0.83
SIM Simple Sarcasm	*Rho*	0.18	0.21	0.02	0.21	-0.05	0.13
	Sig. (2-tailed)	0.42	0.34	0.89	0.32	0.80	0.54
SIM Compex Sarcasm	*Rho*	0.10	0.19	.56**	.59**	.58**	.60**
	Sig. (2-tailed)	0.80	0.40	0.008	0.001	0.006	0.003
SIM Total	*Rho*	-0.06	0.09	0.27	0.42	0.36	0.30
	Sig. (2-tailed)	0.80	0.65	0.19	0.34	0.09	0.15

Note. ACE-R: Addenbrooke's Cognitive Examination Revised; SIM: Social Inference-Minimal Test from TASIT, Rho: Spearman's Correlation Coefficient, Sig.: Significance level. ** Significant at p <.001.

Table 3.14. *Spearman Correlations between ACE-R and TASIT (SIE) Scores*.

		ACE-R Subtests					
		Attention	Memory	Fluency	Language	Visuo-spatial	ACE-R Total
SIE Total	*Rho*	0.07	0.09	0.23	0.27	0.40	0.30
	Sig. (2-tailed)	0.75	0.71	0.31	0.23	0.07	0.17
SIE Visual Cue	*Rho*	-0.01	-0.15	-0.11	-0.02	0.09	-0.07
	Sig. (2-tailed)	0.97	0.52	0.63	0.94	0.69	0.77
SIE Text Cue	*Rho*	-0.09	0.12	0.34	0.27	.05	0.34
	Sig. (2-tailed)	0.69	0.60	0.13	0.23	0.06	0.13

Note. ACE-R: Addenbrooke's Cognitive Examination Revised; SIE: Social Inference-Enriched Test from TASIT, Rho: Spearman's Correlation Coefficient, Sig.: Significance level. ** Significant at p <.001.

Interestingly, five PWD who were unable to complete some or all of the sections in the TASIT, also showed low scores on the ACE-R total score. A comparison between the ACE-R scores of participants, who had been able to complete all sub-tests on the TASIT and those who had not revealed significant differences in their ACE-R total scores U (27)= 107, z= 3.25, p<.001.

3.5. Discussion

3.5.1 Discussion of the Research Findings

3.5.1.1 Summary of Hypotheses

3.5.1.1.1 ***Social cognition*****.** The main purpose of this study was to assess whether in comparison to their partners, PWDs showed lower scores on a social cognition task (i.e. TASIT). The TASIT assesses a wide range of social skills including an individual's ability to identify seven basic emotions, understand and interpret literal conversational remarks, or non-literal remarks and the ability to make judgments about the thoughts, intentions and feelings of speakers (McDonald et al., 2006). Participants with mild to moderate DAT or mixed dementia showed difficulties on all three parts of a social cognition test, the TASIT (ERT, SIM and SIE), compared to their partners' performance. A comparison between PWDs and partners on TASIT-ERT revealed significant differences between both groups' performance on all emotions, with the exception of '*happy*'. Descriptive statistics suggest that partners' scored higher on TASIT-ERT for all emotions in comparison to PWDs, suggesting a better performance compared to PWDs. An examination of

PWDs scores did not reveal a bias towards labelling emotions as '*happy*'. These results support previous research by Gregory et al. (2002) and Kipps et al. (2009a) suggesting DAT are poorer than controls at recognising emotions.

Significant differences were also found between PWDs and partners on TASIT-SIM, which assesses participants' ability to understand what the video vignettes actors' beliefs, meaning, intentions and feelings were. Examination of '*sincere*', '*simple sarcastic*' and '*complex sarcastic*' descriptive values suggested higher scores on this task for partners compared to PWDs. Detection and appropriate interpretation of sarcasm requires a complex process that relies on integration of semantic, syntactic comprehension, contextual and paralinguistic information processing, pragmatic knowledge, visual perspective taking, emotion reading and ToM (Shany-Ur et al., 2012). Considering that PWDs in our study showed significantly lower scores on an emotion recognition task compared to partners, it is not surprising that difficulties arise when PWDs attempt to successfully integrate additional components of social cognition. Four PWD were unable to complete the TASIT-SIM. The most commonly reported difficulties encountered by participants on this task related to memory impairments, i.e. unable to recall the content of the video-vignette.

The TASIT-SIE attempts to further understand the contribution of paralinguistic cues and differentiates between '*textual*' (i.e. speakers in video-vignettes would express their true opinion in a preceding or antecedent dialogue before engaging in a social exchange) and '*visual*' (i.e. visual object) paralinguistic cues in understanding social situations. This task adds additional demands on participants as they are required to recognise emotions, distinguish between sincere

and sarcastic social exchanges and in addition, make use of paralinguistic visual or verbal information to make an informed decision. PWDs showed significantly lower scores on this task compared to their partners. One further participant in the PWD group was unable to complete this task, making the total number of PWD 22. Effect sizes in this task ranged from .73 to .80 suggesting that the exclusion of five participants did not significantly affect the results in this task.

3.5.1.1.2 ***Behaviour and social cognition.*** The second aim of the study was to assess the relationship between proxy-ratings of behaviour (i.e. NPI-D) and social cognition (i.e. TASIT-ERT, SIM, SIE). The link between social cognitive difficulties and behaviour changes in neurodegenerative conditions is yet to be fully established (Elamin et al., 2012). The present study used correlational analyses explore the association. However, no significant associations were found. These results are in contrast with Shimokawa et al. (2001) who found a relationship between interpersonal behaviour (as measured by their own interpersonal behaviour scale) and static facial displays of emotion. Studies with FTD patients have also established this relationship. For instance Gregory et al. (2002) used first and second order ToM tasks in a group of FTD. Interestingly their study also assessed behaviour using NPI-D. These results are in line with Milders et al (2003, 2008) in TBI populations. Milders et al. (2003, 2008) assessed aspects of social cognition, including ToM and emotion recognition in TBI and used proxy-ratings of behaviour to assess their relationship. Similar to the present study, correlational analyses with adjusted alpha levels were used. However, Milders and colleagues (2003, 2008) used a wide range of social cognition assessments and different behavioural rating scales. The present study is the first to examine TASIT scores and NPI–D in DAT or mixed vascular

participants. It is possible that variations in the definitions of '*social cognition'* and '*behaviour change'* and scales used to assess these constructs may account for the inconsistency in results. In addition, while it is possible that the lack of association may be due to validity issues regarding the TASIT as a measure of social cognition in neurodegenerative conditions, the lack of comparable ecologically valid measures in this population and scarcity of studies assessing social cognition and behaviour in DAT make it difficult to draw any definite conclusions.

3.5.1.1.3 ***Social cognition and relationship quality*****.** No statistically significant correlations were found between social cognition in PWDs and their partners' relationship quality ratings. This relationship was initially assessed following a growing evidence base in the field of TBI indicating that social cognition problems can significantly influence interpersonal factors such as relationship functioning or social participation and well-being (Bornhofen & McDonald, 2008). However, no study up to now has assessed this relationship in neurodegenerative conditions. Further exploration of this possible association is important, as evidence suggests that in couples that have received a diagnosis of dementia, positive interactions through communication or personal contact can result in increased emotional wellbeing (Garand et al., 2007), and may subsequently affect their coping.

3.5.1.1.4 ***Behaviour and relationship quality*****.** Relationship quality as measured by the BRCM, was highly correlated with the presence, frequency and severity of behaviour changes in PWDs, particularly delusions, apathy, irritability or disinhibition. These results are particularly important when thinking about supporting an individual following a diagnosis of a possible dementia. In many

services the emphasis is placed on supporting the PWD by providing strategies, medication, psycho-education or social interaction, and support for the partner, carer or family is only addressed as a reactive strategy or if problems arise and a possible breakdown in relationship is likely. Acknowledging the links between behaviour changes in DAT or mixed dementia and relationship continuity may help services prevent such breakdown and crisis situations by providing guidance and support for families and carers and diminish caregiving burden (Department of Health, 2009 & 2008; NICE, 2007; Department of Health, 2000). Placing such emphasis in supporting cares and families would also be in line with current national priorities (Department of Health, 2009 & 2008; NICE, 2007; Department of Health, 2000).

3.5.1.1.5 ***Social cognition and mood symptomatology*****.** The present study also aimed to assess whether performance in a social cognition task in PWDs was associated with partners' self-reported mood. No significant associations were found between those constructs. Although PWDs showed social cognition difficulties, it is possible that these were not significantly severe to have an effect on partners' mood. It is also possible that PWDs compensate for social cognition difficulties in real-life situations by withdrawing or relying on other social and contextual cues. During conversation with couples, it became apparent that most partners' agreed that PWDs needed additional support in social situations to understand sarcasm or others' intentions. However, partners' did not report this as significantly distressing. Qualitative observations of PWDs behaviour in social situations may be useful in understanding the extent of social cognition difficulties in DAT and the ways in which participants and families may have learnt to compensate for those impairments in real-life situations. Most of the evidence relating to partners' or

carers' mood in neurodegenerative conditions or ABI has focused on the effects of behaviour difficulties on caregiver burden or carers' mood symptomatology (Kinsella, Packer, & Olver, 1991); where increased behaviour change has a significantly negative effect on carers' mood. However, many studies include social skills' difficulties in their definition of behaviour changes. Despite the lack of association found in the current study, a further exploration both qualitatively and quantitatively of this relationship may provide further insight into the needs and behaviour of individuals with a neurodegenerative condition and the best support for their carers or partners.

3.5.1.1.6 ***General cognitive ability and social cognition*****.** Interestingly, five PWD unable to complete the TASIT-SIE also scored significantly lower on the ACE-R compared to those who managed to complete all parts of the TASIT. These findings are in line with suggestions by Shany-Ur et al. (2012) that general cognitive decline may be partly responsible for difficulties in social cognition in PWD. Phillips et al. (2010) reported that in order to successfully recognise emotions, individuals needed to rapidly detect the perceptual emotional stimulus and apply higher-level decision making about what verbal descriptor best described a facial expression. It is thus plausible, that emotion recognition skills require intact executive functioning skills, such as higher order decision-making skills (Phillips et al., 2010). There is evidence of a link between perceptual decline and general cognitive ability in DAT (Buck & Radford, 2004). Indeed, on tasks with relatively low cognitive and perceptual requirements, participants with DAT were capable of recognising different emotions from nonverbal sources, including facial expressions (Bucks & Radford, 2004; Burnham & Hogervorst, 2004) and vocal prosody (Bucks & Radford,

2004).

However, most studies on social cognition have opted for a less sensitive (Feher et al., 1992), shorter, general cognitive ability test, the Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) (e.g. Phillips et al., 2010). The MMSE has shown significant sensitivity problems, particularly to frontal, linguistic and early memory difficulties (Feher et al., 1992); as such, results from studies using this measure as a predictor of social cognition should be interpreted with caution, as this scale may not fully capture impairments in executive and working memory functioning, which form part of an individual's general cognitive skills. In addition, future research including anatomical data examining the neural substrate of these deficits and their relative contributions would be valuable and may clarify the distinction between social cognition difficulties and general cognitive impairment due to progressive neurodegeneration.

The association between general cognitive ability and social cognition in DAT was further assessed by looking at associations between ACE-R scores and TASIT (ERT, SIM and SIE) scores in PWDs. Correlational analyses suggested higher cognitive abilities in PWDs were significantly related to better emotion recognition skills (TASIT-ERT total) in PWDs. Interestingly, the recognition of positive emotions was associated with the attention, language and overall general cognitive ability scores in PWDs, while recognition of negative emotions did not appear to correlate with sub-tests of the ACE-R, but did correlate with total ACE-R score. There is growing evidence of a dichotomy in PWDs' ability to recognise postitive versus negative emotions (Adolphs, 2001). This dichotomy is accompanied by evidence of distinct neural substrates for positive versus negative emotion perception and processing within the brain (Adolphs, 2001). Lesion studies appear to

show the amygdala is essential in the recognition of emotions from facial expressions, particularly negatively valenced emotions such as fear (Adolphs, 2001). Developmentally, the amygdala has played a crucial role in human survival, by provided almost automatic responses to negative emotions. On the other hand, Rosen et al. (2003) have indicated an association between recognition of positive emotions and damage to the frontal regions of the brain, particularly in the behavioural variant of FTD. The present study's results appear to provide tentative evidence of distinct cognitive pathways to the recognition of positive versus negative emotions; it is possible that the processing of positive emotions requires a cognitive element, not essential in the automatic 'fight or flight' processing of negative emotions.

In addition, general cognitive ability was also significantly correlated to an understanding of complex sarcastic social situations, particularly the fluency, language and visuo-spatial subtests of the ACE-R. However, no significant correlations were found between total ACE-R scores and TASIT SIE subtests. A prerequisite to understanding complex sarcasm in social situations involves ToM. An individual cannot solely rely on language to process complex sarcasm, but needs additional elements, such as visual cues and flexible thinking to be able to understand these situations. Beer et al. (2006) have suggested the prefrontal cortex plays a crucial role in decision-making, online monitoring and processing of social situations, hence it is possible that the associations observed in the current study are a reflection of widerspread damage to the prefrontal regions of the brain.

Unfortunately, this study did not include an in depth cognitive and social cognition assessment, thus it is not possible to further disentangle the association between

social cognition and general cognitive ability further.

3.5.1.2 Sample Characteristics.

The age of PWDs in our sample ranged from 71 to 94 years. Similarly, partners' age in the present study ranged from 65 to 96 years old. Studies assessing social cognition in DAT (e.g. Shany-Ur et al., 2012; Gregory et al., 2002; Kipps et al., 2009ab) have tended to use younger DAT populations; in particular, studies using the TASIT with individuals with a diagnosis of DAT have included DAT participants aged around 60 years old (e.g. Shany-Ur et al., 2012). Although DAT is not exclusive to older people, it is typically diagnosed between the ages of 65 and 80 years (Alzheimer Society, 2012). The inclusion of only '*young-old*', i.e. older people aged 65 to 75 years old, in studies of social cognition brings into question the representativeness of samples in older people research and highlights the need to include '*older-old*' individuals, above 75 years old, in future research.

In line with existing evidence on prevalence of neuropsychiatric symptoms such as anxiety in PWD (e.g. Mahoney, Regan, Katona, & Livingtone, 2005) and their partners (e.g. Lykestos et al., 2002), three partners and two PWDs reported levels of anxiety on the HADS higher than the recommended cut-off score of eight (Bjelland, Dahl, Tangen Haug, & Neckelmann, 2002). In contrast to previous studies on depression symptomatology in PWDs and their partners (e.g. Mahoney et al., 2005) suggesting prevalence rates of depression around 10 per cent, only one partner (no PWD) reported depression symptomatology on the HADS in the present study. The difference may be due to a bias in sample selection. The SDCRN, from which our sample was recruited, regularly assess their volunteers on factors such as mood and general cognitive and maintain very close bonds with Clinical Psychology and

Older Age Psychiatry specialists in the area, who can offer them support and advice. It is possible that this regular contact may provide volunteers in the SDCRN panel support in managing their own mood difficulties and hence may explain such low depression symptomatology scores. It is also possible that people with significant levels of depression avoid joining a volunteer panel and participating in research, suggesting a bias in volunteer panel studies.

Prevalence of behavioural issues as measured by the NPI-D for PWD in our study were 74 per cent '*apathy*', 51 per cent '*anxiety*', 45 per cent '*irritability*' and 37 per cent '*agitation*' and '*appetite changes*'. Consistent with previous studies using the NPI-D in DAT populations (e.g. Lykestos et al., 2002), '*apathy*' and '*agitation*' appear as the most prevalent symptoms in DAT populations. A discrepancy can be noted between self-reported levels of anxiety and depression in PWDs as measured on the HADS and proxy-ratings of anxiety as measured by the NPI-D. Bierman and colleagues (2007) suggested a negative association between self-reported anxiety and depression symptomatology and moderate to severe cognitive decline typically found in DAT. It is possible that lack of insight (Bierman et al., 2007) may explain the discrepancy; as an individual with DAT cognitively deteriorates, so does their insight and awareness into their deficits; and a lack of insight may result in lower anxiety and depression (Bierman et al., 2007). Unfortunately, the present study did not assess insight and awareness into participant's difficulties; therefore it is not possible to assess this hypothesis.

3.5.2 Strengths and Limitations of the Study.

Common to most studies in neurodegenerative conditions is the issue of

sample size (Wilson et al., 2000). Recruitment in studies involving participants with neurodegenerative conditions faces significant challenges (Wilcock et al., 2007) that can ultimately affect the statistical power of a given research. Failure to achieve the necessary sample size will ultimately affect the statistical power of a study, i.e. the long term probability of rejecting the null hypothesis, and may increase the chances of Type II error (Cohen, 1992). Previous studies assessing social cognition and behaviour in neurodegenerative conditions, have recruited smaller or equal sample sizes to those found in the present study. Several studies have opted for amalgamating participants with different neurodegenerative conditions into one group. For example, Rankin et al. (2009) combined participants with different neurodegenerative aetiologies into a group and subsequently divided them into either '*pass*' or '*fail*' depending on their performance on a social cognition task. However, this methodology does not appear to allow researchers to investigate the discreet differences between conditions in depth. The present study focused primarily on DAT, but due to uptake in the recruitment regions, individuals with a diagnosis of mixed DAT and vascular dementia were also included.

It is possible that some of the difficulties in social cognition noted in the study's sample may be accounted for by vascular accidents in the frontal regions of the brain; however, this is unlikely to explain all of the impairments found in the present study. It is possible that fatigue may have impacted on participants' performance on these tasks. Issues of fatigue were managed by counterbalancing tests and introducing regular breaks between testing.

The sample in this study was collected from two main regions across

Scotland, and recruitment was limited to volunteers from the SDCRN. It is possible that this recruitment procedure may not provide a realistic clinical sample of PWD attending services and may not reflect the types of referrals made to clinical services. Achieving a representative and significant sample size in neurodegenerative conditions such as dementia research is often difficult given practical limitations, which are often posed on researchers. Several charities and focused networks have developed volunteer lists (i.e. SDCRN), whereby participants with a specific condition can enrol and may be contacted regarding the possibility of taking part in research. Although this recruitment process offers great advantages in terms of time and access, it also highlights important issues regarding representativeness of a sample (i.e. there is the possibility that participants who enrol in volunteer panels may share similar traits, not necessarily similar to the rest of the population) and learnt responses through repetition of assessment in various studies, which may further bias results of a study. Unfortunately, studies in the area of dementia do not routinely indicate the number of participants approached; hence it is not possible to compare uptake in the present study with similar studies.

Finally, a recurrent issue with inclusion of healthy controls are '*ceiling'* effects in cognitive tests, whereby all or most participants score at the highest end of a cognitive scale. As a consequence, general cognitive assessments, which are aimed at detecting impairments in cognitive functioning, will often show skewed scores in healthy controls (Morris, 1999), affecting the statistical analyses that can be used (Field, 2009). In line with previous research on social cognition and behaviour change (e.g. Kipps et al., 2009 a,b), the current study used non-parametric analyses to examine the data. While non-parametric statistical tests have often been criticised

for difficulties in achieving power, it should be highlighted that this is only a difficulty when the parametric assumptions are still tenable (Field, 2009). As with the present study, in the cases where the parametric assumptions have been violated, for reasons such as small sample size or '*ceiling effects'*, non-parametric statistics would be preferable due to their robustness, i.e. as they make fewer assumptions.

3.5.3 Future Directions

Only the TASIT was used to assess social cognition in this study. Considering the lack of a normative sample for older people on this task, it would have been beneficial to include additional ToM and emotion processing tasks in order to establish concurrent reliability and be able to determine '*impaired*' performance and cut-off scores by examining standardised scores allowing for more detailed statistical methodology.

A significant issue assessing older people relates to the scarcity of normative samples in neuropsychological tests. Five patients had to be excluded from our analyses in the present study due to this issue. For instance, the TASIT does not currently have valid norms or cut-off points for older people, and several neuropsychological assessments (e.g. ACE-R) only have standardised norms till the age of 75years (Mioshi et al., 2006). With increasing life expectancy, neuropsychological assessments need to accommodate for '*older-old*', i.e. over 75 years of age and provide adequate normative samples, in order to detect neuropsychological impairment, monitor change or identify specific difficulties in the '*older-old*' (Morris, Worsley & Matthews, 2000). Considering current

governmental initiatives (e.g. NICE, 2012 or Dementia Strategy, 2011) and improvements in pharmacological treatments for dementia; a comprehensive neuropsychological assessment may prove important in monitoring change in the near future (Morris, Worsley & Matthews, 2000). Consequently, tests need to be psychometrically suitable for testing older people. Future studies should aim to establish normative scores for older people.

From a clinical perspective, and despite spreading testing over several sessions, both participants and partners reported feeling fatigued towards the end of the task and future studies need to consider the effects of fatigue on the scores obtained, especially when lengthy neuropsychological assessments are used. In addition, it is clear from the literature that social cognition and behaviour encompass a wide range of phenomena. Different studies appear to define these constructs in varying terminology, making comparisons across studies very difficult. For instance, Shimokawa et al (2001) assessed interpersonal behaviour, i.e. subtle social skill changes. Among the factors included in the assessed behaviour changes, Shimokawa et al. (2001) also included items such as '*how awkward ward staff found the patient'*, which incur a level of subjectivity. In contrast, other studies have used measures such as the NPI-D, which assess behaviours including '*agitation*', '*aggression*', '*hallucinations*' or '*delusions*', among other behaviour changes. Therefore, consistency regarding which behaviour and social cognition measures are used, and a shared understanding of these constructs, should be adopted in future studies in order to allow comparisons across studies.

3.5.4 Clinical Implications

This is the first study to assess the relationship between social cognition, behaviour and relationship quality in DAT. Previous research has commented on the lack of research available on the relationship between these factors (e.g. Kipps et al., 2009ab, Shany-Ur et al., 2012); this study provides valuable information and clinical implications.

Approximately 90 per cent of individuals with dementia may experience BPSD as part of their illness (Alzheimer's Society, 2011), causing significant distress to the individual and their family and carers. The National Institute for Clinical Excellence (NICE, 2012) and the Scottish Intercollegiate Guidelines Network (SIGN, 2006) advise that individuals presenting with changes in behaviour should be comprehensively assessed in order to understand possible triggers and factors affecting the behaviour and should receive individually tailored care-plan to help manage the behaviour and alleviate distress on carers and family members. The guidance suggests that staff and families caring for individuals with dementia should be appropriately trained and should receive psycho-education (NICE, 2012) on strategies to manage social and behaviour changes such as distraction or diversion techniques or use of online monitoring of performance through carers feedback.

However, a greater understanding of predictors of interpersonal, social and behaviour changes in DAT may help carers and families understand some of the difficulties their relatives may be suffering and help them adapt their communication and interpersonal style to match the participants' understanding. This may also significantly improve caregiving burden and care. The present study has highlighted

the need to use concrete language, avoid analogies and sarcasm and state clearly the emotions a person is feeling when interacting with individuals with a diagnosis of DAT or mixed dementia. This is due to their difficulties recognising emotions and understanding sincere or sarcastic situations. By using literal language, carers, family and professionals may decrease individuals with a diagnosis of DAT or mixed dementia's possible level of confusion regarding social scenarios.

With regard to the assessment of social cognition, the TASIT's lengthy duration may pose difficulties in clinical settings, when time is limited. When queries arise regarding an individual's social cognitive abilities, proxy reports of individual's behaviour in social situations may be considered instead. In addition, the present study has shown a significant association between social cognition and general cognitive ability in DAT or mixed dementia. Practitioners should bear in mind that difficulties with social cognition may arise with progression of a neurodegenerative condition. As such, health professionals and families may benefit from adapting their communication to avoid abstract language in the moderate to severe stages of the disease progression.

Social skills training groups (e.g. Group Interactive Social Training [GIST, Dalhberg et al., 2007]) have been successfully used in ABI to improve social communication and quality of life by improving individual's insight into their own difficulties and using role play scenarios. However, neither SIGN (2006) or NICE (2012) include evidence on the use of social skills groups in dementia. The present study adds to the body of evidence that social cognition may be impaired in individuals with dementia and further research should aim to replicate and adapt

social skills groups in this population in order to overcome some of these difficulties.

In addition, NICE (2012) recommend cognitive behavioural therapy (CBT) for managing anxiety and depression in participants with a diagnosis of dementia. Bearing in mind the importance of emotions, behaviour and interpersonal relationships in psychotherapy, it is crucial for professionals to have a clear understanding of their participants' presenting difficulties as well as their social cognitive abilities in order to be able to formulate and adapt therapy following a person-centred model of care.

Early diagnosis of dementia remains a key government target together with appropriate intervention and support throughout the course of the disease (Department of Health, 2009). An understanding of social cognition and behaviour changes in DAT could help provide a differential and timely diagnosis between different conditions and introduce support services with an aim to prevent and manage BPSD throughout the progression of the disease.

From a neurocognitive and neuropsychological perspective, the study of social cognition and behaviour in neurodegenerative conditions allows researchers to stage and possibly anatomically correlate disease progression with cognitive skills and changes, hence providing further understanding of brain regions and functioning.

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5. Appendices

Appendix A. Systematic Review

Critical Evaluation Form

Table 1. Prorated Scoring of items 3, 4 and 12.

Table 2. Description of Social Cognition Measures Used in the Included Studies.

Table 3. Description of Behaviour Measures Used in the Included Studies.

CRITICAL EVALUATION FORM (Adapted from CREST)

Reviewer:
Date:

Paper being evaluated:

Authors:

Journal, volume and pages:

Year:

PAPER CHARACTERISTICS

Main Research Question:

Secondary Research Question(s):

Research Approach (descriptive, correlational, comparative, quasi-experimental, randomised, repeated measures, qualitative):

Main Statistical Analyses:

QUALITY CRITERIA

1. Clear rationale for investigating emotion identification and behavioural difficulties in stroke, brain injury or neurodegenerative conditions is clearly discussed.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

2. The sample is well described and frequencies reported for clinical and demographic characteristics such as age, gender or time since diagnosis. The frequency distribution, central tendency (means, medians, modes and standard deviations) and dispersion (range) of the sample are reported.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

3. Caution has been taken to make sure that the sample is representative of the population, the number of participants approached, the number of individuals who participated and how the sample was selected is reported. Inclusion and exclusion criteria should also be clearly described. Differences in demographic variables such as age, gender, education or IQ are explored.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

4. When a control group is used, they should be matched in all aspects other than the factors under investigation, for example age, education or premorbid IQ scores. It is clear what control groups are controlling for and why they are appropriate.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

5. An internationally recognised classification system should be used for individuals included in the research who are identified as having a stroke, a brain injury or a neurodegenerative condition.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

6. The study indicates how many of the participants in each group who were asked to take part in the study actually managed to complete each or all measures, i.e. it gives an indication of missing data.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

7. The study gives a rationale for the choice of tests employed.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

8. Attrition rates are reported for each of the groups studied.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

9. Reliability and validity are reported for the emotion identification measure. *Reliability: What reliability is reported (e.g. test-re-test, parallel form, internal, inter-rater and intra-rater)? What is the magnitude of the reliability coefficient (at least 0.7)? Validity: What type of validity is reported (e.g. content, face, factorial, concurrent, empirical, predictive or incremental)? What is the magnitude of the validity coefficients (at least 0.7)?*

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

10. Reliability and validity are reported for assessments looking at individual's behaviour. *Reliability: What reliability is reported (e.g. test-re-test, parallel form, internal, inter-rater and intra-rater)? What is the magnitude of the reliability coefficient (at least 0.7)? Validity: What type of validity is reported (e.g. content, face, factorial, concurrent, empirical, predictive or incremental)? What is the magnitude of the validity coefficients (at least 0.7)?*

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

11. Statistical power of the study is addressed.

Power and sample sizes are explicitly investigated before the study started, and the values reported were reasonable (power of more than 0.8). Post hoc power is reported for negative key findings, where necessary.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

12. Generalisability of the findings is discussed, as well as implications and limitations of the study.

Well covered (3)	Adequately addressed (2)	Poorly addressed (1)	Not addressed (0)	Not applicable (0)
Comments:				

Total:

Table 1. Prorated scoring for items 3, 4 and 12 of the Quality Assessment.

Quality Criteria		**3**			**4**				**12**		
Author, Date, Country	**a**	**b**	**c**	**Prorated Total (a,b,c)**	**d**	**e**	**Prorated Total (d,e)**	**f**	**g**	**h**	**Prorated Total (f,g,h)**
Milders, et al. (2008), UK	AA (++)	PA (+)	WC (+++)	AA (++)	WC (+++)	WC (+++)	WC (+++)	AA (++)	PA (+)	WC (+++)	AA (++)
Gregory, et al. (2002), UK	PA (+)	NA (0)	AA (++)	PA (+)	PA (+)	PA (+)	PA (+)	AA (++)	AA (++)	AA (++)	AA (++)
Milders, et al. (2003), UK	AA (++)	PA (+)	WC (+++)	AA (++)	WC (+++)	WC (+++)	WC (+++)	AA (++)	PA (+)	WC (+++)	WC (+++)
Rankin, et al. (2009), USA	PA (+)	WC (+++)	AA (++)	AA (++)	WC (+++)	PA (+)	AA (++)	AA (++)	AA (++)	AA (++)	AA (++)
Shimokawa, et al., (2001), Hon Kong	WC (+++)	WC (+++)	NA (0)	AA (++)	NA (0)	NA (0)	NA (0)	PA (+)	PA (+)	PA (+)	PA (+)
Shany-Ur, et al. (2012), USA	AA (++)	PA (+)	WC (+++)	AA (++)	AA (++)	NA (0)	PA (+)	AA (++)	AA (++)	AA (++)	AA (++)
Kipps, et al. (2009b), UK	AA (++)	PA (+)	WC (+++)	AA (++)	WC (+++)	PA (+)	AA (++)	PA (+)	PA (+)	PA (+)	PA (+)
Kipps, et al. (2009a), UK	AA (++)	PA (+)	WC (+++)	AA (++)	AA (++)	AA (++)	AA (++)	WC (+++)	AA (++)	PA (+)	AA (++)
Girardi, et al. (2011a), UK	NA (0)	PA (+)	AA (++)	PA (+)	AA (++)	AA (++)	AA (++)	AA (++)	PA (+)	NA (0)	PA (+)
Girardi, et al. (2011b), UK	NA (0)	PA (+)	AA (++)	PA (+)	AA (++)	AA (++)	AA (++)	AA (++)	PA (+)	NA (0)	PA (+)
Keane, et al. (2002), UK	NA (0)	NA (0)	WC (+++)	PA (+)	NA (0)	AA (++)	PA (+)	NA (0)	PA (+)	AA (++)	PA (+)
Sturm & Levenson (2011), USA	PA (+)	NA (0)	AA (++)	PA (+)	WC (+++)	PA (+)	AA (++)	AA (++)	PA (+)	WC (+++)	AA (++)

Hornak, et al. (1996), UK	NA (0)	NA (0)	NA (0)	NA (0)	NA (0)	AA (++)	PA (+)	PA (+)	AA (++)	NA (0)	PA (+)

Note. a: Representativeness of sample, b: Inclusion and exclusion criteria, c: exploration of differences between groups, d: matched samples, e: Rationale for sample selected explained, f: Generalisability, g: Implications, h: Limitations.
Ratings: WC, well covered (+++); AA, adequately addressed (++); PA, poorly addressed (+); NA, not addressed (0); NAA, not applicable (0)

Table 2. *Description of the Social Cognition Measures Used in the Included Studies*.

Emotion Recognition Measure	Description and Social Cognitive Skill Measured
Benton Facial Recognition Test (BFRT, Benton et al., 1983)	There are two versions of this test. The shorter version has 13 items with 27 possible points, while the longer version has 22 items with 54 possible points. On each item, subjects are presented with a target photo and asked to recognise the target individual from six faces presented simultaneously. There are three parts to the BFRT: (i) matching a frontal view, (ii) matching a frontal view of the target individual with three photos taken from different angles, and (iii) matching a frontal view of the target individual with three taken under different lighting conditions. No time limits are placed on the BFRT.
Comprehensive Affect Testing System (CATS, Froming et al., 2001)	Computerised measure of visual and auditory emotional processing of six basic emotions. The CATS consists of thirteen subtests assessing facial identification, emotion matching with and without verbal denotation, emotional tone or prosodic processing with and without verbal denotation, and with conflicting or congruent semantic content.
Cartoon Test (Happé et al., 1999)	This test includes 12 cartoons of humorous situations. In six cartoons the joke is assessing ToM, while on the remaining six cartoons the joke is based on a physical anomaly. Individuals are asked to explain why the joke is funny.
Ekman Face Recognition Test (EFRT, Ekman & Friesen, 1976)	Black and white photographs of individuals depicting one of six emotions: happy, sad, angry, fearful, disgusted or surprised. Individuals are required to recognise facial expressions of emotion.
Emotional Empathy Questionnaire (EEQ, Mehrabian & Epstein, 1972)	Thirty-three item questionnaire that assesses various aspects of emotional empathy, i.e. the ability to understand the emotional states of others and one's own role in the mental states of others (Eslinger, 1998).
Emotion Hexagon (Calder et al., 1996)	This task contains morphed facial expressions taken by Ekman and Friesen (1976) pictures of facial emotions, which are presented in a continua ranging between the following six facial expression pairs: happiness-surprise, surprise-fear, fear-sadness, sadness-disgust, disgust-anger and anger-happiness. Participants are presented with 30 morphed faces in a random order and asked to identify which of the six emotions (i.e. happy, sad, anger, surprised, fearful, disgust) best represented the facial expression shown.
Emotion Recognition Test (Shimokawa et al., 2001)	Improved version of the ERT (Shimokawa et al., 2000) containing more questions and changing the pictures showing expressions and situations. The main emotions assessed are: happy, sad, anger, fear and surprise. Individuals are asked to match the target face

	with one of four alternatives. In addition to testing visuo-perceptual skills, it also assesses individuals' ability to comprehend verbal labels of emotion, facial emotions and emotional situations.
Faux Pass Test (Stone et al., 1998)	Vignette tasks that depict individuals doing or saying something without considering the consequences on others. This task is designed to assess components of ToM.
Facial Expression of Emotion Stimuli and Test (FEEST, Young et al., 2002)	Subjects are presented with a set of 30 morphed photographs. Each face shows two of the six basic emotions (happiness, surprise, fear, sadness, disgust and anger) with different degrees of intensity. Subjects were instructed to categorise each morphed face according to one of the six basic emotions (i.e. happy, sad, anger, surprised, fearful, disgust).
Famous Faces Recognition Test (Keane et al., 2002)	Participants are shown 30 pictures of highly familiar faces and ten unfamiliar faces presented in a fixed pseudo-random order. Individuals are required to recognise the familiar faces, give their name and occupation.
Florida Affect Battery (FAB, Bowers, Blonder & Heilman, 1998)	The FAB was designed to assess the perception of facial and prosodic affect under a variety of task demands. This battery includes 10 different subtests (5 facial, 3 prosodic, and 2 cross-modal). Five different emotions (happiness, sadness, anger, fear, and neutral) are used across these subtests.
First and Second Order False Belief Test (Wimmer, 1985; Baron Cohen, 1989)	Vignette, cartoon or video based tasks that depict situations where individuals hold false beliefs (first order) or where individuals hold false beliefs about another individual's beliefs or knowledge.
Gaze Processing Test (Keane et al., 2002)	Forced-choice task used to determine eye-gaze direction. Pairs of photographs of the same person were presented, and participants are required to identify which one of the two pictures is looking towards them. For one third of the pairs, both pictures are full-face pictures, the other pairs showed pictures where individuals were looking either 20° to the right or the left.
Iowa Gambling Test (IGT, Bechara, Tranel & Damasio, 2000)	Computerised task whereby participants are presented four decks of cards, which can be associated with either winning or loosing money. The goal of this task is to win as much money as possible by learning to avoid the 'loosing' card decks.
Judgment of Preference Task (E-Prime Task, from Baron-Cohen et al., 1995 and Snowden et al., 2003)	Individuals are presented with a cartoon face in the centre of four items. In the 'control' condition, the cartoon face is looking at one of the four pictures and participants are asked ' what picture is the cartoon face looking at?' In the 'test' condition, the cartoon face is smiling and is looking at one of the items. Participants are then asked 'what picture of the four doe the

	cartoon face likes most?'
Reading the Mind in the Eye Test (Baron-Cohen et al., 1997)	Individuals are shown photographs of the eye region of actors depicting complex mental states (e.g. despondent) and asked to select between four possible options to describe how the person in the photograph is feeling.
Recognition of Vocal Emotions (Keane et al., 2002)	This test comprises a series of 60 non-verbal sounds, which convey six basic emotions including happiness, sadness, anger, fear, surprise and disgust. Participants are asked to choose from a printed list of emotions, which one of them is related to the sound being played.
Test of Awareness and Social Inference Test (TASIT, McDonald, 2003)	Audio-visual tool designed for the clinical assessment of social perception with alternate forms for retesting. Part 1 assesses emotion recognition; Parts 2 and 3 assess the ability to interpret conversational remarks meant literally (i.e., sincere remarks and lies) or non-literally (i.e., sarcasm) as well as the ability to make judgments about the thoughts, intentions and feelings of speakers.
Toronto Alexithymia Scale-20 (TAS-20, Bagby, Parker & Taylor, 1994)	The TAS-20 is a 20-item self-report instrument to assess alexithymia. Total scores range between 20 and 100, and higher scores mean a higher tendency toward alexithymia. The TAS-20 consists of three factors: 1) difficulty in identifying feelings and distinguishing them from the bodily sensations of emotions (DIF); 2) difficulty in describing feelings to others (DDF); 3) externally oriented cognitive style of thinking (EOT).

Table 3. *Description of Behaviour Measures Used in the Included Studies*.

Behaviour Measure	Description
Cambridge Behaviour Inventory (CBI, Bozeat et al., 2000)	Informant-based questionnaire including 81-items aimed at assessing behavioural changes across a range of neurodegenerative disorders. This questionnaire was designed to capture cognitive, behavioural and affective symptoms as well as activities of daily living (ADL) and evaluates 13 functional/behavioural domains: memory, orientation and attention, everyday skills, self care, mood, challenging behaviour, disinhibition, eating habits, sleep, stereotypic and motor behaviour, motivation, insight and awareness. The CBI rates the frequency of any particular behaviour on a scale of 0-4. A score of zero denotes no impairment, a score of 1 an occasional occurrence, 2 a repeated occurrence, 3 a daily occurrence, and 4 constant occurrence; the latter two scores signifying a severe behavioural deficit
Dysexecutive Questionnaire (DEX, Wilson et al., 1996)	Twenty-item questionnaire, designed to sample a range of problems such as emotional or personality changes, motivational changes, behavioural changes, and cognitive changes. The DEX comes in two formats: patient and caregiver. Items are scored on a 5-point Likert scale (0-4) ranging from 'Never' to 'Very often', with higher scores indicating more problems.
Emotional Lability Questionnaire (ELQ, Newsom-Davis et al., 1999)	This 33-item questionnaire is administered via a structured interview and assesses frequency, duration of episodes, relation to external events, degree of voluntary control, congruence with mood state and subsequent distress of patients with pathological laughter and crying and emotional lability. There are two possible formats: Self-report by patient, proxy completion by caregiver in parallel version.
Frontal Systems Behavior Scale (FrSBe, Grace & Maloy, 2001)	Forty six-item rating scale designed to measure frontal systems in behavioural syndromes. It also quantifies behavioural change over time by including both baseline (retrospective) and a current assessment of behaviour.This scale includes a total score, which is a composite of three subscales: apathy, disinhibition, and executive dysfunction. Two test booklets are available: self-rating and rating by a family member or caregiver. Two profile forms (Self and Family) allow comparisons of behaviours pre- and post-injury/illness.
Katz Adjustment Scale revised (KAS-R, Goran & Fabiano, 1993)	Proxy rating questionnaire consisting of 127 items designed to obtain observer ratings of community

	adjustment. Items are rated on a 4-point Likert-type scale ranging from 1, which indicates almost never, to 4 for almost always. Item responses were summed within each factor.
Interpersonal Behaviour Checklist (Shimokawa et al., 2001)	This scale rates the degree of indifference for interpersonal relationships on five items: stay with others, speak to others, answer to other who speak to him/her, care for others, greet others. Each of these items is rated on a 4-point scale. Either family members or staff members, who know the individual well, rate behaviour.
Interpersonal Reactivity Index (IRI, Davis, 1980)	This is a 28-item questionnaire that includes 7-item sub-scales assessing different aspects of empathy. Informants are asked to rate 28 statements on a scale from 1 (does not describe the behaviour at all) to 5 (describes very well), and the total scale ranges from 7 to 35.
Manchester Behavior Questionnaire (MBQ, Bathgate et al., 2001)	Semi-structured questionnaire that covers the following domains: basic and social emotions, social behaviour, response to sensory stimuli, eating and other oral behaviours, wandering behaviour, sexuality, sleep pattern, repetitive behaviours, compulsions and rituals, environmental dependency, memory and spatially-related behaviours, delusions and hallucinations The questionnaire is administered to primary carers of patients, normally the spouse or partner.
Neuropsychology Behaviour and Affect Profile (NBAP, Nelson et al., 1998)	106-item questionnaire specifically designed to assess the emotional and behavioural consequences of ABI. The Self version is completed by patients and the Observer version by a relative or significant other. Each item is rated in relation to premorbid and post injury behaviour as 'agree', meaning typically or often, or 'disagree', meaning seldom or hardly at all. 'Agree' is scored as 1 and 'disagree' as 0. Item scores are allocated to one of five subscales (indifference, inappropriateness, pragnosia, depression, mania) and are summed into a Total NBAP score. Higher scores indicate more behavioural problems
Neuropsychiatric Inventory (NPI, Cummings, 1997)	This scale assesses ten behavioural disturbances occurring in dementia patients: delusions, hallucinations, dysphoria, anxiety, agitation/ aggression, euphoria, disinhibition, irritability/ lability, apathy, and aberrant motor activity. The NPI uses a screening strategy to minimise administration time, examining and scoring only those behavioural domains with positive responses to screening questions. Both the frequency and severity of each behaviour can be determined.

	Information for the NPI is obtained from a caregiver familiar with the patient's behaviour.
Social Integration Questionnaire (SIQ, Willer, Ottenbacher, & Coad's, 1994)	Adapted from Willer, Ottenbacher, and Coad's (1994) Community Integration Questionnaire (CIQ). This questionnaire assesses three aspects of social outcome: home integration (involvement in household work), social integration (involvement in social activities) and work integration. Each item is rated as '*Yes*' or '*No*.' '*Yes*' is scored as 1, '*No*' as 0. This questionnaire can be completed by both the patient and a relative
Subjective Emotional Change Questionnaire (Hornak, et al., 1996)	This scale asks each patient whether they have noticed any changes since their surgery/head-injury/illness, any change in either the intensity or the frequency of their own experience or emotions. They are also asked about their experience in their daily life. The questionnaire is usually administered orally to the patient while they are alone with the tester so there is no opportunity for the patient to confer with a spouse, friend or relative about how they should answer the questions. Any change reported, whether an increase or a decrease in frequency or intensity is scored as follows: a small change, 0.5; a change, 1.0; a big change, 1.5. Each patient was then given a total score across all emotions, regardless of whether the change represents an increase or decrease in the emotions that have changed.
Staff Behaviour Questionnaire (Hornak, et al., 1996).	Proxy-rated questionnaire devised for patients after surgery/head-injury/illness, which rates the individual's behaviour in a variety of situations including meal-time, occupational therapy and behaviour on the ward.

Appendix B. Empirical Paper

Participant information sheet, version 9, 18.04.12

Partner information sheet version 3, 31.05.12

Consent form, version 7, 18.04.12

Demographic questionnaire participant, version 3, 18.04.12

Demographic questionnaire, version 3, 18.04.12

Cover letter, version 7, 31.05.12

SDCRN Letter, 25.06.12

R&D Management approval-NHS Health Board A, 19.06.12

R&D Management approval NHS Health Board B, 26.06.12

Ethical Approval Letter, 25. 05.12

Emotion Identification and Relationship Quality in Dementia

Participant Information Sheet

We invite you to participate in a research project. We believe it to be of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand firstly why we are doing it, and secondly what it would involve if you agreed. We are therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

- **Who has reviewed the study?**

The Scotland Research Ethics Committee which has responsibility for scrutinising all proposals for medical research on humans in , has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Edinburgh and NHS , whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

- **What is the study about?**

This study will look at individuals' ability to identify emotions, for example happiness, sadness, anger, etc. The way we identify different emotions is very important as it is related to the way we socialise and interact with others. If we weren't able to identify emotions we wouldn't be able to tell if people were sad or happy and we wouldn't be able to interact appropriately with others.

In the past however, most studies have asked participants to look at a series of pictures of people and say what emotion they are showing. This is not a very reliable way to study emotion identification as when people are happy or sad they display more than just a smile or tears. People use their body and their language to express how they are feeling and this cannot be shown in pictures or photos only.

This study will use a different technique, it will ask participants to look at a series of video clips and then answer some questions about what they have just seen.

- **Why have I been asked to take part?**

You have been asked to take part as you are registered with the Scottish Dementia Clinical and Research Network database and have said in the past that you would be happy to be contacted about research projects.

- **What will I be asked to do?**

I would like to meet with you on a maximum of **3** occasions. We will meet at days, venues and times that are suitable and convenient for you.

The first time we meet, we will talk more about the study and I will answer any questions you may have. You will then have **1 week** to decide if you would like to take part. You can talk to your friends and family about the study. With your consent, we will inform your General Practitioner (GP) that you are taking part in this study.

If you agree to take part, we can arrange where and when to meet for a second time. The second time we meet, I will ask you some questions, do some tasks and watch some DVD clips. I will also ask you to complete a questionnaire that will ask you about your mood. This will not take more than 90 minutes (1 hour and a half) and you will be offered breaks throughout.

The tasks will involve some:

- Memory tasks, for example remembering a name and address

- Naming tasks, for example naming some drawings
- Copying some figures and drawing tasks

We may need to meet more than once; this may be in case you feel tired or need to stop earlier. We can arrange subsequent meetings to suit you. However, we will not meet more than 3 times.

If there are any questions you don't want to answer or any tasks that you don't want to do it's OK, you don´t have to answer or take part.

If it is OK with you, I will write down your answers. This is so I can remember what you told me. However, the information that I collect from you will be kept secure. This means that your name or contact details will not be available to anyone other than myself and my supervisors.

The information I collect will be written up as part of my Clinical Psychology training course and may be published. This information will be anonymised, so no one will be able to identify you except for myself and my supervisors.

- **Do I have to take part in the study?**

Your participation is entirely voluntary.If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form.

Taking part in the study will not affect the care you receive from any NHS service now or in the future.

At any point during this study, if you no longer wish to participate, you can withdraw from the study without giving me or anoyone a reason why.

- **What are the possible benefits of taking part?**

Although you will not receive any direct benefits, this study aims to provide recommendations at a local and national level about how older people services can be a better support for partners and individuals with dementia.

- **What are the disadvantages or risks of taking part?**

If you feel fatigued or would like to stop earlier, we may need to meet more than once. We can arrange subsequent meetings to suit you. However, we will not meet more than 3 times.

- **Will my taking part in the study be kept confidential?**

My supervisors (Dr. Fiona Macleod, Dr. Kenneth Laidlaw and Professor Kevin Power) and I (Blanca Poveda) will be allowed to see the information that I collect from you. Once we have completed all the tasks, your name and any identifiable information will be removed. This means that no one will be able to tell it's you.

With your consent, we will inform your General Practitioner (GP) that you are taking part in this study.

The information I gather from you will be kept for 3 years after the research has been completed according to NHS Research Ethic's Guidelines.

If you tell me anything that makes me think that you are at risk of harm, or others around you are at risk, I would discuss what to do next with you.

- **Will I find out the results of the study?**

If you wish to know the results of the study we can provide you with a written summary of the study. If you prefer, we can arrange to meet you at a place and time that suits you and I can tell you the results.

- **What will happen to the results of the study?**

I will share my results with my supervisors (Dr. Laidlaw, Dr. Macleod and Prof. Power). I may also write the results of the study for publication in a scientific journal. This will be totally anonymous, and no participants will be identifiable by name.

- **Who is organising the research and why?**

I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS [redacted]. I am carrying out this

research as part of my training to become a Clinical Psychologist.

- **Who has reviewed the study?**

The study proposal has been reviewed by the University of Edinburgh Doctorate in Clinical Psychology course and my supervisors (Dr. Fiona Macleod, Dr. Kenneth Laidlaw and Professor Kevin Power). A favourable ethical opinion has been obtained from the [redacted] Scotland Research Ethics Committee. NHS management approval has also been obtained.

- **I want to know more about the study...What should I do?**

If you wish to take part, please read through the consent form provided and we can arrange a time and place to meet to start the research. If you prefer to take this information back home and would like to meet to discuss the study further we can also arrange for this.

You can also phone me (Blanca Poveda) to talk more about this.
Phone: [redacted]

- **I don't agree with the study...What should I do?**

If you don't agree with any parts of this study and would like to make a complaint, you can do this through the NHS [redacted] Complaints Procedure:

Write a letter to and send it to: Patient Liaison Manager
Complaints Office,
[redacted]
Phone: [redacted]

Or by talking to my supervisor: Dr. Fiona Macleod
Consultant Clinical
Psychologist/ Lead Clinician
[redacted]

Phone: 01356 692 806

Or by talking to an independent advisor:

Mrs. Alison Peaker
Consultant Clinical
Psychologist/ Lead Clinician
[redacted]
NHS
[redacted]
Phone: [redacted]

Thank you for taking the time to read this information sheet.

Partner Information Sheet, Version 3, Dated 31.05.12

Emotion Identification and Relationship Quality in Dementia

Participant Information Sheet

We invite you to participate in a research project. We believe it to be of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand firstly why we are doing it, and secondly what it would involve if you agreed. We are therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

- **Who has reviewed the study?**

The Scotland Research Ethics Committee , which has responsibility for scrutinising all proposals for medical research on humans in , has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Edinburgh and NHS , whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

- **What is the study about?**

This study will look at individuals' ability to identify emotions, for example happiness, sadness, anger, etc. The way we identify different emotions is very important as it is related to the way we socialise and interact with others. If we weren't able to identify emotions we wouldn't be able to tell if people were sad or happy

and we wouldn't be able to interact appropriately with others.

In the past however, most studies have asked participants to look at a series of pictures of people and say what emotion they are showing. This is not a very reliable way to study emotion identification as when people are happy or sad they display more than just a smile or tears. People use their body and their language to express how they are feeling and this cannot be shown in pictures or photos only.

This study will use a different technique, it will ask participants to look at a series of video clips and then answer some questions about what they have just seen.

- **Why have I been asked to take part?**

You have been asked to take part as you are registered with the Scottish Dementia Clinical and Research Network database and have said in the past that you would be happy to be contacted about research projects.

- **What will I be asked to do?**

I would like to meet with you on a maximum of **3** occasions. We will meet at days, venues and times that are suitable and convenient for you.

The first time we meet, we will talk more about the study and I will answer any questions you may have. You will then have **1 week** to decide if you would like to take part. You can talk to your friends and family about the study. You and your partner will both need to provide consent to participate in the study. With your consent, we will inform your General Practitioner (GP) that you are taking part in this study.

If you agree to take part, we can arrange where and when to meet for a second time. The second time we meet, I will ask you some questions, do some tasks and watch some DVD clips. I will also ask you to complete three questionnaires, one will ask you about your mood, one will ask you about your relationship with your partner and the last questionnaire will ask you about your partner's behaviour. This will not take more than 90 minutes (1 hour and a half) and you will be offered breaks throughout.

The tasks will involve some:

- Memory tasks, for example remembering a name and address
- Naming tasks, for example naming some drawings
- Copying some figures and drawing tasks

We may need to meet more than once; this may be in case you feel tired or need to stop earlier. We can arrange subsequent meetings to suit you. However, we will not meet more than 3 times. If there are any questions you don't want to answer or any tasks that you don't want to do it's OK, you don´t have to answer or take part.

If it is OK with you, I will write down your answers. This is so I can remember what you told me. However, the information that I collect from you will be kept secure. This means that your name or contact details will not be available to anyone other than myself and my supervisors.

The information I collect will be written up as part of my Clinical Psychology training course and may be published. This information will be anonymised, so no one will be able to identify you except for myself and my supervisors.

- **Do I have to take part in the study?**

Your participation is entirely voluntary. If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form.

At any point during this study, if you no longer wish to participate, you can withdraw from the study without giving me or anyone a reason why.

- **What are the possible benefits of taking part?**

Although you will not receive any direct benefits, this study aims to provide recommendations at a local and national level about how older people services can be a better support for partners and individuals with dementia.

- **What are the disadvantages or risks of taking part?**

If you feel fatigued or would like to stop earlier, we may need to meet more than once. We can arrange subsequent meetings to suit you. However, we will not meet more than 3 times.

- **Will my taking part in the study be kept confidential?**

My supervisors (Dr. Fiona Macleod, Dr. Kenneth Laidlaw and Professor Kevin Power) and I (Blanca Poveda) will be allowed to see the
information that I collect from you. Once we have completed all the tasks, your name and any identifiable information will be removed. This means that no one will be able to tell it's you.

With your consent, we will inform your General Practitioner (GP) that you are taking part in this study.

The information I gather from you will be kept for 3 years after the research has been completed according to NHS Research Ethic's Guidelines.

If you tell me anything that makes me think that you are at risk of harm, or others around you are at risk, I would discuss what to do next with you.

- **Will I find out the results of the study?**

If you wish to know the results of the study we can provide you with a written summary of the study. If you prefer, we can arrange to meet you at a place and time that suits you and I can tell you the results.

- **What will happen to the results of the study?**

I will share my results with my supervisors (Dr. Laidlaw, Dr. Macleod and Prof. Power). I may also write the results of the study for publication in a scientific journal. This will be totally anonymous, and no participants will be identifiable by name.

- **Who is organising the research and why?**

I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS [redacted] I am carrying out this

research as part of my training to become a Clinical Psychologist.

- **Who has reviewed the study?**

The study proposal has been reviewed by the University of Edinburgh Doctorate in Clinical Psychology course and my supervisors (Dr. Fiona Macleod, Dr. Kenneth Laidlaw and Professor Kevin Power). A favourable ethical opinion has been obtained from the [redacted] Scotland Research Ethics Committee. NHS management approval has also been obtained.

- **I want to know more about the study...What should I do?**

If you wish to take part, please read through the consent form provided and we can arrange a time and place to meet to start the research. If you prefer to take this information back home and would like to meet to discuss the study further we can also arrange for this.

You can also phone me (Blanca Poveda) to talk more about this.
Phone: [redacted]

- **I don't agree with the study...What should I do?**

If you don't agree with any parts of this study and would like to make a complaint, you can do this through the NHS [redacted] Complaints Procedure:

Write a letter to and send it to: Patient Liaison Manager
Complaints Office,
[redacted]
Phone: [redacted]

Or by talking to my supervisor: Dr. Fiona Macleod
Consultant Clinical
Psychologist/ Lead Clinician
[redacted]
Phone: [redacted]

Or by talking to an independent advisor:

Mrs. Alison Peaker
Consultant Clinical
Psychologist/ Lead Clinician
[redacted]
NHS
[redacted]
Phone: [redacted]

Thank you for taking the time to read this information sheet.

Consent Form , Version 7, Dated 18.04.12

Emotion Identification and Relationship Quality in Dementia

Participant consent form

(Please initial each box if you agree with the statement)

I have read over the Participant Information Sheet ☐

I have had a chance to talk to someone about the study ☐

I know that I do not have to take part in this study and that I can stop at any time. I will not have to tell anyone why I want to leave the study. ☐

I know that taking/ not taking part in the study will not affect the care I receive from any Services, either presently or in the future ☐

I understand that this study involves meeting with Blanca up to **3** times. ☐

I understand that my family doctor will be notified about my participation in this study. ☐

I understand that all information given by me in this study will remain confidential ☐

I would like to receive a written summary of the key findings ☐

Consent Form , Version 7, Dated 18.04.12

Emotion Identification and Relationship Quality in Dementia

I agree to take part in this study ☐

(*please initial*)

Participant Name:_____

Signature:_____

Date:_____

Witness Name:_____

Signature:_____

Date:_____

Researcher Name:_____

Signature:_____

Date:_____

Demographic Questionnaire, Version 3, 18.04.2012

Demographic Questionnaire (participants with dementia group). The Chief Investigator will be asking the questions to the participants and writing their responses down.

Code	e.g. T1001I or T1001P
Gender	
Date of Birth	
Sensory difficulties Do they wear glasses? Do they have any visual difficulties? Handedness Do they have any hearing difficulties?	
Diagnosis When was diagnosis made? What professional diagnosed them? How they feel it has affected them? Have they noticed any difficulties?	☐ GP ☐ Psychiatrist, ☐ Psychologist
Education At what age did they leave full time education?	
Occupational History Are they working? Retired? If so… When did they retire? What was their occupation?	
Support Network How many friends or family are they regularly in contact with?	
Marital Status Are they married/	

divorced/ single/ separated/ living with someone/ widowed? If married/ with partner… How long have they been together?	
Quality of Life In a scale from 1 to 10 (1 = not satisfied and 10= very satisfied) how satisfied are they with their life?	1-------2-------3-------4-------5-------6-------7-------8-------9-------10 not satisfied very satisfied
Medical history Do they have any physical health difficulties? Any traumatic brain injuries in the past? Are they currently on any medication for any conditions? Are they currently being seen by a professional? Are they currently undergoing any medical investigation or treatment?	
History of mood Would they consider themselves depressed? Have they ever been depressed? Have they ever been treated for depression?	
Smoker/ Alcohol	
Additional Information	

Demographic Questionnaire, Version 3, 18.04.2012

Demographic Questionnaire (partner group). The Chief Investigator will be asking the questions to the participants and writing their responses down.

Code	e.g. T1001I or T1001P
Gender	
Date of Birth	
Sensory difficulties Do they wear glasses? Do they have any visual difficulties? Handedness Do they have any hearing difficulties?	
Diagnosis How they feel the diagnosis has affected them? Have they noticed any difficulties or changes in their partner's behavior or personality? Have they noticed any difficulties or changes in their cognition?	
Education At what age did they leave full time education?	
Occupational History Are they working? Retired? If so… When did they retire? What was their occupation?	
Support Network How many friends or family are they regularly in contact with?	
Marital Status Are they married/ divorced/ single/	

separated/ living with someone/ widowed? If married/ with partner… How long have they been together?	
Quality of Life In a scale from 1 to 10 (1 = not satisfied and 10= very satisfied) how satisfied are they with your life?	1-------2-------3-------4-------5-------6-------7-------8-------9-------10 not satisfied very satisfied
Medical history Do they have any physical health difficulties? Any traumatic brain injuries in the past? Are they currently on any medication for any conditions? Are they currently being seen by a professional? Are they currently undergoing any medical investigation or treatment?	
History of mood Would they consider themselves depressed? Have they ever been depressed? Have they ever been treated for depression?	
Smoker/ Alcohol	
Additional Information	

Cover Letter, Version 7, Dated 31.05.12

Emotion Identification and Relationship Quality in Dementia

Dear Participant,

My name is Blanca Poveda. I am training to be a Clinical Psychologist at the University of Edinburgh and work for NHS [redacted] As part of my training I am carrying out a study looking at people´s ability to identify emotions. I would like to invite you to take part in this study. I have been given your details by the Scottish Dementia Clinical Research Network. I will be calling you over the next week to discuss with you if you would like to participate in my study.

I would like to tell you why the study is being carried out and what you would be required to do as part of this study.

I have attached an information sheet for you to read. Please read the following information carefully, or be sure that someone reads it to you, and please feel free to ask any questions you may have about the study when we speak or by contacting me on the number below.

It is important that you are aware that you do not need to decide whether or not to take part straight away and you can talk to your friends and family about it.

Thank you for taking the time to read this,

Yours sincerely,

Blanca Poveda
Trainee Clinical Psychologist
University of Edinburgh/ NHS [redacted]
b.poveda@nhs.net
[redacted]

Psychiatry of Old Age
Murray Royal Hospital
Muirhall Road
Perth
PH2 7BH
Telephone Number: 01738 562322
Fax Number: 01738 562481

Miss Blanca Poveda
Older People Psychological Therapies Service

Our Ref NAN 24
Enquiries to Philip Brown, Administrator
Direct Line 01738 562322
E mail philipbrown1@nhs.net

25th June, 2012

Dear Miss Poveda

We have considered your study 'Relationship Quality in Dementia' for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study for the following support:

- Access to patient data
- Access to carer data

We wish you every success in your project.

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Kind regards.

Yours sincerely

EMMA LAW
Manager
Scottish Dementia Clinical Research Network

cc Dr F MacLeod

19 June 2012

Miss Blanca Poveda
Trainee Clinical Psychologist
[redacted]

Dear Miss Poveda,

R & D MANAGEMENT APPROVAL – [redacted]

Title: Effects of emotion identification abilities and behavioural difficulties on relationship quality in participants with dementia and their partners.

Chief Investigator: Miss Blanca Poveda **Principal Investigator: Miss Blanca Poveda**

[redacted] Ref: 2012MH06 **NRS Ref: NRS12/MH70**

REC Ref: 12/ES/0045

Sponsor: University of Edinburgh

Funder: Unfunded

Many thanks for your application to carry out the above project here in NHS [redacted] I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in [redacted]

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- All amendments to be notified to TASC R & D Office.
- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS [redacted] where required (http://www.nihr.ac.uk/systems/Pages/systems_research_passports.aspx).
- TASC R & D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.
- Notification to TASC R & D Office of any change in funding.
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.

Version 3 – 15/03/12

- All eligible studies will be added to the UKCRN Portfolio http://public.ukcrn.org.uk/. Recruitment figures for eligible studies must be recorded onto the Portfolio every month: This is the responsibility of the lead UK site. If you are the lead, or only, UK site, we can provide help or advice with this. For information, contact Charles Weller – (01382) 7 40128 – charles.weller@nhs.net or Liz Livingstone – (01382) 7 40126 – elivingstone@nhs.net.

- Annual reports are required to be submitted to TASC R & D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.

- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R & D Office.

- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

Approved Documents

Document	Version	Date
NHS SSI Form (89158/319156/6/764/124539/242455)		30/04/12
NHS R&D Form (89158/319698/14/877)		30/04/12
Ethics – Evidence of Compliance		04/06/12
Ethics – Favourable Ethical Opinion		25/05/12
Participant Information Sheet	10	31/05/12
Partner Information Sheet	3	31/05/12
Consent Form	7	18/04/12
Cover Letter	7	31/05/12
GP Letter	3	18/04/12
Demographic Questionnaire (Participants with Dementia Group)	3	18/04/12
Demographic Questionnaire (Partner Group)	3	18/04/12
Protocol Disclosure Flowchart	5	18/04/12
Participant Recruitment Pathway	4	20/03/12
Protocol	6	03/04/12
Insurance Certificate – University of Edinburgh		01/08/11 to 31/07/12
CV – Blanca Poveda Mozolowski		03/05/12

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R & D Office should you require further assistance.

Yours sincerely

Elizabeth Coote
R&D Manager

Version 3 – 15/03/12

University Hospitals Division

NHS

[redacted]

CPP/SS/approval

26 June 2012

Miss Blanca Poveda
Psychological Therapies
[redacted]

Research & Development
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343

Email: R&DOffice@luht.scot.nhs.uk

Director: Professor David E Newby

Dear Miss Poveda

[redacted] **R&D Project No:** 2012/P/PSY/17

Title of Research: Effects of emotion identification abilities and behavioural difficulties on relationship quality in participants with dementia and their partners

REC No: 12/ES/0045

CTA No: N/A

Eudract: N/A

Patient Information Sheet: Version 10 dated 31 May 2012
Partner Information Sheet: Version 3 dated 31 may 2012

Consent Form: Version 7 dated 18 April 2012

Protocol: Version 6 dated 3 April 2012

I am pleased to inform you that this study has been approved for NHS [redacted] and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS [redacted]

Please note that the NHS [redacted] R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

Dr Christine P Phillips
Deputy R&D Director

Cc Paul Dearie, QA Manager

EoSRES

Amended 31/05/2012

NHS SCOTLAND

[redacted] Scotland Research Ethics Service (EoSRES) REC 1
(formerly [redacted] Committee on Medical Research Ethics A/B)
[redacted] Medical Sciences Centre (TASC)
Residency Block C, Level 3
[redacted] Hospital & Medical School
[redacted]

Miss Blanca Poveda
[redacted]

Date: 25 May 2012
Your Ref:
Our Ref: LR/12/ES/0045
Enquiries to: Mrs Lorraine Reilly
Extension: [redacted]
Direct Line:
Email: lorraine.reilly@nhs.net

Dear Miss Poveda

Study title: **Effects of emotion identification abilities and behavioural difficulties on relationship quality in participants with dementia and their partners.**

REC reference: **12/ES/0045**

The Research Ethics Committee reviewed the above application at the meeting held on 18 May 2012. Thank you for attending to discuss the study and conveying Professor Power's apologies.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

You clarified the following points. There is no requirement to respond unless there are any inaccuracies:

1. The Committee were a little unclear regarding the recruitment strategy – Miss Poveda confirmed that participants had already volunteered to be included in research and confirmed there was an active database with checks in place to ensure that participants were still suitable to take part in research i.e. their dementia had not progressed to a moderate range and still had partners.

2. The Committee questioned what would happen if one of the participants did not consent to take part in the study – Miss Poveda confirmed that both partners have to agree to take part in the study or they would be excluded as the study was looking at relationship qualities.

Further information or clarification required

The following points require to be addressed by letter and submission of revised documentation where requested. **Please note that there is no requirement to amend your application form.**

1. Regarding the application form:

POSITIVE ABOUT DISABLED PEOPLE

- The Committee felt the contact by phone from the researcher could perhaps be perceived as cold calling.
- The Committee were unclear how long between being added to the database would the research team approach.

2. Regarding the Participant Information Sheet (PIS):
   - It should be made clear in the Information Sheet that partners also have to give consent prior to inclusion in the study.
   - Under 'Do I have to take part? – 'anoyone' should read 'anyone'.
   - Please delete from the Carers Information Sheet 'your treatment will not be affected'.
3. Regarding the Letter of Invitation:
   - 'Make a decision' should be changed to 'decide whether or not to take part'

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with

updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of insurance or indemnity		01 August 2011
GP/Consultant Information Sheets	3	18 April 2012
Investigator CV		03 May 2012
Letter of invitation to participant	6	03 April 2012
Other: Letter from Emma Law		12 April 2012
Other: Letter from Mrs Anne Fernon		20 January 2012
Other: Letter regarding funding		17 January 2012
Other: Disclosure Management Pathway	5	18 April 2012
Other: CV - Dr Fiona MacLeod		
Other: CV - Dr Ken Laidlaw		13 February 2012
Other: CV Professor Kevin Power		07 May 2012
Participant Consent Form	7	18 April 2012
Participant Information Sheet: Participant	9	18 April 2012
Participant Information Sheet: Partner	2	18 April 2012
Protocol	6	03 April 2012
Questionnaire: Partner Demographic Questionnaire	3	18 April 2012
Questionnaire: Participants Demographic Questionnaire	3	18 April 2012
REC application	89158/319695/1/956	30 April 2012
Summary/Synopsis	4	20 March 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/ES/0045	**Please quote this number on all correspondence**

Yours sincerely

L. Reilly

for **Dr Carol Macmillan**
Chair

Email: lorraine.reilly@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.
"After ethical review – guidance for researchers"

Copy to: Marianne Laird, University of Edinburgh
NHS Tayside R&D Office

Appendix C: Descriptive, Normality and Variances Tables

Table 1. *Carers' Skewness and Kurtosis Statistics for Time Since Diagnosis, Age, Years Married and Total Scores on WTAR, BRCM, ACE-R, NPI-D, HADS and TASIT (Part I, II and III).*

	Skewness		Kurtosis	
	Statistic (*z*-score)	Standard Error	Statistic (*z*-score)	Standard Error
Age	1.75	0.45	1.92	0.87
Years married	-2.64*	0.45	2.56*	0.87
WTAR raw score	-1.43	0.45	0.06	0.87
WTAR scaled score	-1.08	0.45	-0.02	0.87
ACE-R total	-1.63	0.45	-0.67	0.87
BRCM	-1.58	0.45	-0.25	0.87
HADS-A	1.18	0.45	-0.98	0.87
HADS-D	1.20	0.45	1.35	0.87
NPI-D total score	6.75**	0.45	12.46**	0.87
NPI-D distress	3.35**	0.45	2.75*	0.87
TASIT EET positive	-0.41	0.45	-1.42	0.87
TASIT EET negative	-4.14**	0.45	-1.42	0.87
TASIT EET final	-0.35	0.45	-0.72	0.87
TASIT SIM do total	-1.37	0.45	0.16	0.87
TASIT SIM say total	-1.18	0.45	0.33	0.87
TASIT SIM think total	-0.49	0.45	-0.80	0.87
TASIT SIM feel total	-2.13*	0.45	1.42	0.87
TASIT SIM sincere	-0.34	0.45	-1.59	0.87
TASIT SIM sarcasm	-1.85	0.45	0.27	0.87
TASIT SIM paradoxical	-3.48**	0.45	3.53**	0.87
TASIT SIM final	-0.87	0.45	-0.03	0.87
TASIT SIE do	-2.09*	0.45	0.91	0.87
TASIT SIE say	-1.03	0.45	-0.15	0.87
TASIT SIE think	-1.27	0.45	-0.70	0.87
TASIT SIE feel	-1.14	0.45	-0.40	0.87
TASIT Total visual sarcasm	-2.29*	0.45	0.29	0.87

TASIT Total visual cue lie	-2.96*	0.45	2.97*	0.87
TASIT Total text sarcasm	-1.25	0.45	-0.08	0.87
TASIT Total text lie	-2.04*	0.45	0.43	0.87
TASIT Final visual	-1.91	0.45	-0.33	0.87
TASIT Final text	-4.88**	0.45	7.35**	0.87

Note. WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; BRCM: Birmingham Relationship Continuity Measure; NPI-D: Neuropsychiatric Inventory; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).
* Values significant at $p<0.05$.
** Values significant at $p<0.001$.

Table 2. *Patients' Skewness and Kurtosis Statistics for Age and Total Scores on WTAR, BRCM, ACE-R, NPI-D, HADS and TASIT (Part I, II and III).*

	Skewness		Kurtosis	
	Statistic (*z*-score)	Standard Error	Statistic (*z*-score)	Standard Error
Age	1.32	0.45	-0.04	0.87
WTAR raw score	-1.26	0.45	-0.85	0.87
WTAR scaled score	-1.23	0.45	-0.75	0.87
ACE-R total	-0.69	0.45	-1.23	0.87
HADS-A	1.60	0.45	-0.07	0.87
HADS-D	-0.49	0.45	-0.43	0.87
TASIT EET positive	0.96	0.46	0.36	0.89
TASIT EET negative	0.04	0.46	-1.27	0.89
TASIT EET final	0.54	0.46	-0.35	0.89
TASIT SIM do total	-0.38	0.48	-0.83	0.93
TASIT SIM say total	-1.35	0.48	-0.29	0.93
TASIT SIM think total	-1.17	0.48	0.65	0.93
TASIT SIM feel total	-2.06*	0.48	0.61	0.93
TASIT SIM sincere	0.28	0.48	-0.48	0.93
TASIT SIM sarcasm	-0.02	0.48	-0.50	0.93
TASIT SIM paradoxical	-1.68	0.48	-0.34	0.93
TASIT SIM final	-2.25*	0.48	1.13	0.93
TASIT SIE do	0.44	0.49	-0.76	0.95
TASIT SIE say	2.66*	0.49	1.43	0.95
TASIT SIE think	0.82	0.49	0.70	0.95
TASIT SIE feel	0.44	0.49	-1.41	0.95
TASIT Total visual sarcasm	-0.96	0.49	0.45	0.95
TASIT Total visual cue lie	0.83	0.49	-0.63	0.95
TASIT Total text sarcasm	-0.26	0.49	-1.23	0.95
TASIT Total text lie	-1.74	0.49	1.37	0.95
TASIT Final visual	0.40	0.49	0.38	0.95
TASIT Final text	-0.12	0.49	-1.02	0.95

Note. WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).
* Values significant at $p<0.05$.

Table 3. *Normality Tests for Carers' Time Since Diagnosis, Age, Years Married and Total Scores on WTAR, BRCM, ACE-R, NPI-D, HADS and TASIT (Part I, II and III).*

	Kolmogorov-Smirnov			Shapiro-Wilk.		
	Statistic	df	Sig.	Statistic	df	Sig.
Years since diagnosis	0.16	27	0.07	0.93	27	0.06
Age	0.17	27	0.05	0.94	27	0.12
Years married	0.21	27	0**	0.87	27	0**
WTAR raw score	0.11	27	0.20	0.95	27	0.22
WTAR scaled score	0.12	27	0.20	0.95	27	0.26
BRCM	0.15	27	0.15	0.94	27	0.16
ACE-R	0.19	27	0.02*	0.90	27	0.07
HADS-A	0.22	27	0**	0.90	27	0.02*
HADS-D	0.15	27	0.13	0.93	27	0.08
NPI-D total score	0.26	27	0**	0.67	27	0**
NPI-D distress	0.19	27	0.01*	0.86	27	0**
TASIT EET positive	0.19	27	0.01*	0.88	27	0.01*
TASIT EET negative	0.25	27	0**	0.80	27	0**
TASIT EET final	0.18	27	0.02*	0.93	27	0.06
TASIT SIM do total	0.21	27	0**	0.93	27	0.09
TASIT SIM say total	0.16	27	0.08	0.95	27	0.20
TASIT SIM think total	0.15	27	0.13	0.96	27	0.34
TASIT SIM feel total	0.19	27	0.02*	0.92	27	0.03*
TASIT SIM sincere	0.15	27	0.12	0.89	27	0.01*
TASIT SIM sarcasm	0.17	27	0.04*	0.94	27	0.09
TASIT SIM paradoxical	0.21	27	0.01*	0.86	27	0**
TASIT SIM final	0.11	27	0.20	0.97	27	0.57
TASIT SIE do	0.20	27	0.01*	0.90	27	0.02*
TASIT SIE say	0.8	27	0.03*	0.92	27	0.03*
TASIT SIE think	0.22	27	0**	0.92	27	0.03*
TASIT SIE feel	0.17	27	0.04*	0.93	27	0.05

TASIT Total visual sarcasm	0.23	27	0**	0.87	27	0**
TASIT Total visual cue lie	0.26	27	0**	0.85	27	0**
TASIT Total text sarcasm	0.28	27	0**	0.87	27	0**
TASIT Total text lie	0.21	27	0**	0.89	27	0.01*
TASIT Final visual	0.17	27	0.04*	0.93	27	0.08
TASIT Final text	0.24	27	0**	0.79	27	0**

Note. WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; BRCM: Birmingham Relationship Continuity Measure; NPI-D: Neuropsychiatric Inventory; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).
* Values significant at $p<0.05$.
** Values significant at $p<0.001$.

Table 4. *Normality Tests for Patients' Age and Total Scores on WTAR, BRCM, ACE-R, NPI-D, HADS and TASIT (Part I, II and III).*

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Age	0.17	22	0.12	0.95	22	0.36
WTAR raw score	0.16	22	0.14	0.88	22	0.01*
WTAR scaled score	0.15	22	0.20	0.90	22	0.03*
ACE-R	0.14	22	0.20	0.93	22	0.14
HADS-A	0.13	22	0.20	0.94	22	0.15
HADS-D	0.19	22	0.04*	0.93	22	0.11
TASIT EET positive	0.17	22	0.12	0.94	22	0.17
TASIT EET negative	0.12	22	0.20	0.96	22	0.50
TASIT EET final	0.09	22	0.20	0.96	22	0.47
TASIT SIM do total	0.12	22	0.20	0.96	22	0.40
TASIT SIM say total	0.15	22	0.20	0.95	22	0.37
TASIT SIM think total	0.15	22	0.20	0.95	22	0.37
TASIT SIM feel total	0.18	22	0.06	0.93	22	0.10
TASIT SIM sincere	0.19	22	0.03*	0.96	22	0.43
TASIT SIM sarcasm	0.12	22	0.20	0.96	22	0.53
TASIT SIM paradoxical	0.14	22	0.20	0.89	22	0.02*
TASIT SIM final	0.14	22	0.20	0.95	22	0.34
TASIT SIE do	0.12	22	0.20	0.96	22	0.52
TASIT SIE say	0.27	22	0**	0.84	22	0**
TASIT SIE think	0.13	22	0.20	0.97	22	0.62
TASIT SIE feel	0.15	22	0.20	0.92	22	0.06
TASIT Total visual sarcasm	0.15	22	0.20	0.96	22	0.43
TASIT Total visual cue lie	0.18	22	0.08	0.95	22	0.39
TASIT Total text sarcasm	0.10	22	0.20	0.98	22	0.94
TASIT Total text lie	0.15	22	0.20	0.94	22	0.16
TASIT Final visual	0.20	22	0.02*	0.94	22	0.19

TASIT Final text	0.16	22	0.16	0.95	22	0.33

Note. df: degrees of freedom; Sig.: significant level; WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).
* Values significant at $p<0.05$.
** Values significant at $p<0.001$.

Table 5. *Carers' Descriptive Statistics for Time Since Diagnosis, Age, Years Married and Total Scores on WTAR, BRCM, ACE-R, NPI-D, HADS and TASIT (Part I, II and III).*

	n	Range	Mean	SD
Years since diagnosis	27	1-8	3.37	1.69
Age	27	65-96	78	6.22
Years married	27	22-73	51.82	10.83
WTAR raw score	27	32-50	43.22	4.54
WTAR scaled score	27	92-125	112.74	8.52
ACE-R total	27	81-100	92.70	5.95
BRCM	27	23-108	76.04	22.39
HADS-A	27	1-12	4.96	3.12
HADS-D	27	0-11	4.11	2.40
NPI-D total score	27	0-60	10.22	12.20
NPI-D distress	27	0-29	7.15	7.06
TASIT EET positive	27	8-12	10.44	1.25
TASIT EET negative	27	9-16	14.26	1.53
TASIT EET final	27	20-28	24.70	2.03
TASIT SIM do total	27	9-15	12.44	1.42
TASIT SIM say total	27	8-15	12.22	1.69
TASIT SIM think total	27	8-15	11.56	1.89
TASIT SIM feel total	27	7-15	12.56	1.91
TASIT SIM sincere	27	14-20	17.30	2.20
TASIT SIM sarcasm	27	8-20	15.52	2.97
TASIT SIM paradoxical	27	7-20	16.11	2.97
TASIT SIM final	27	38-58	49.70	5.01
TASIT SIE do	27	10-16	13.89	1.45
TASIT SIE say	27	11-16	13.85	1.32
TASIT SIE think	27	10-16	13.29	1.65
TASIT SIE feel	27	10-16	13.44	1.67
TASIT Total visual sarcasm	27	10-16	14.10	1.70
TASIT Total visual cue lie	27	8-16	13.89	1.85

TASIT Total text sarcasm	27	8-15	12.44	1.62
TASIT Total text lie	27	10-16	14.18	1.62
TASIT Final visual	27	22-31	27.96	2.74
TASIT Final text	27	12-31	26.33	3.87

Note. WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; BRCM: Birmingham Relationship Continuity Measure; NPI-D: Neuropsychiatric Inventory; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).

Table 6. Patients' Descriptive Statistics for Age, Years Married and Total Scores on WTAR, ACE-R, HADS and TASIT.

	n	Range	Mean	SD
Age	27	71-94	80.26	5.56
WTAR raw score	27	29-48	40.37	5.92
WTAR scaled score	27	86-123	108.11	11.19
ACE-R total	27	41-83	65.09	13.44
HADS-A	27	0-10	3.89	2.78
HADS-D	27	0-8	4.04	2.17
TASIT EET positive	26	3-12	6.12	2.29
TASIT EET negative	26	3-14	8.5	3.17
TASIT EET final	26	7-26	14.62	4.79
TASIT SIM do total	23	3-14	8.87	2.93
TASIT SIM say total	23	3-13	8.93	2.70
TASIT SIM think total	23	3-13	8.60	2.31
TASIT SIM feel total	23	2-13	8.96	2.77
TASIT SIM sincere	23	9-20	14.17	3.05
TASIT SIM sarcasm	23	2-20	10.83	4.69
TASIT SIM paradoxical	23	0-15	10.17	4.33
TASIT SIM final	23	11-47	35.17	8.99
TASIT SIE do	22	4-13	8.50	2.60
TASIT SIE say	22	6-14	8.70	2.10
TASIT SIE think	22	4-14	8.45	2.26
TASIT SIE feel	22	5-12	8.18	2.36
TASIT Total visual sarcasm	22	2-14	9.05	2.87
TASIT Total visual cue lie	22	4-14	8.77	2.83
TASIT Total text sarcasm	22	1-12	6.95	3.12
TASIT Total text lie	22	2-14	9.55	2.89
TASIT Final visual	22	10-27	17.82	4.01
TASIT Final text	22	8-24	16.05	4.80

Note. WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).

Table 7. *Levene's Homogeneity of Variance Test for Time Since Diagnosis, Age, Years Married and Total Scores on WTAR, ACE-R, HADS and TASIT.*

	Levene´s Statistic	df1	df2	Sig
Age	0.11	1	52	0.92
WTAR raw score	2.09	1	52	0.15
WTAR scaled score	1.72	1	52	0.20
ACE-R total	16.70	1	52	0**
HADS-A	0.39	1	52	0.53
HADS-D	1.03	1	52	0.32
TASIT EET positive	6.36	1	51	0.02*
TASIT EET negative	19.32	1	51	0**
TASIT EET final	14.52	1	51	0**
TASIT SIM do total	13.22	1	48	0**
TASIT SIM say total	4.27	1	48	0.04*
TASIT SIM think total	0.25	1	48	0.62
TASIT SIM feel total	1.83	1	48	0.18
TASIT SIM sincere	0.87	1	48	0.36
TASIT SIM sarcasm	3.73	1	48	0.06
TASIT SIM paradoxical	5.30	1	48	0.03*
TASIT SIM final	6.37	1	48	0.02*
TASIT SIE do	8.21	1	47	0.01*
TASIT SIE say	1.97	1	47	0.92
TASIT SIE think	1.14	1	47	0.03*
TASIT SIE feel	5.34	1	47	0.03*
TASIT Total visual sarcasm	5.42	1	47	0.02*
TASIT Total visual cue lie	5.67	1	47	0.02*
TASIT Total text sarcasm	14.96	1	47	0**
TASIT Total text lie	4.10	1	47	0.05*
TASIT Final visual	2.10	1	47	0.16
TASIT Final text	3.16	1	47	0.08

Note. df: degrees of freedom; Sig.: significant level; WTAR: Wechsler Test of Adult Reading; ACE-R: Addenbrooke's Cognitive Examination Revised; TASIT: The Awareness of Social Inference Test; EET: Emotion Recognition (TASIT Part I); SIM: Simple Sarcasm (TASIT Part II); SIE: Complex Sarcasm (TASIT Part III).
* Values significant at $p<0.05$.
** Values significant at $p<0.001$.

Total word count excluding references and appendices: 22,343